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ACTION FOR CHILDREN AFFECTED BY AIDS

Programme profiles and lessons learned

A Joint WHO/UNICEF Document

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Programme profiles and lessons learned

World Health Organization
Geneva

United Nations Children's Fund
New York

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FOREWORD

The AIDS pandemic is tragically affecting the lives of children worldwide. Family structures are being disrupted. Growing numbers of infants are being born with HIV infection. Millions more are being orphaned by the death of their mother, or both parents, from AIDS. In parts of Africa, the number of child-headed households is rising alarmingly. All too often, orphans drop out of school and join the ranks of street kids. Wherever the rights of women and children are violated or under attack, the consequences of HIV/AIDS are particularly dramatic. Surviving women and their children are discriminated against, often to the point of losing their property—including the family home.

To make matters worse, the countries most affected by HIV/AIDS are often already weakened by civil war, drought, famine or other natural disasters. The resulting social upheaval not only makes it harder to cope with the impact of AIDS but also fosters the further spread of HIV.

The pandemic has thus given rise to a host of problems for children. Fortunately, a growing number of programmes around the world are responding to their special needs. Because both these needs and the responses are in many ways unprecedented, it is crucial that the lessons learned in responding to children affected by HIV/AIDS should be documented and shared with those who will be facing similar needs in the years ahead. By presenting this survey of programmes that have addressed themselves to AIDS–affected children, we hope to contribute to the experience-sharing process, and help stimulate and guide action to mitigate the impact of the pandemic on children.

This document is meant above all for those who carry responsibility for responding to the many challenges posed by HIV/AIDS, including policy makers at all levels, programme planners, and those working directly with affected individuals and families. For many others with an interest in children, the information presented should raise awareness of the pandemic's profound consequences for this most vulnerable population group.

No one can as yet fully appreciate how devastating this pandemic will prove to be. As precious experience accumulates, all of us must learn from one another how we can best contribute to curbing the further spread of the virus and mitigating its destructive impact.

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CHILDREN AND AIDS: A GLOBAL PERSPECTIVE

AIDS is in many ways a family disease. In the areas most affected by the pandemic, the makeup of families and communities is changing as more and more adults in their most productive years become ill and die, leaving the young and the elderly to cope alone.

In rural villages, haunting images are repeated in home after home: the oldest child nursing a sick parent and trying to keep the family together, grandparents struggling to provide for clusters of grandchildren, families taking in orphaned* children, groups of siblings living on their own without adult care.

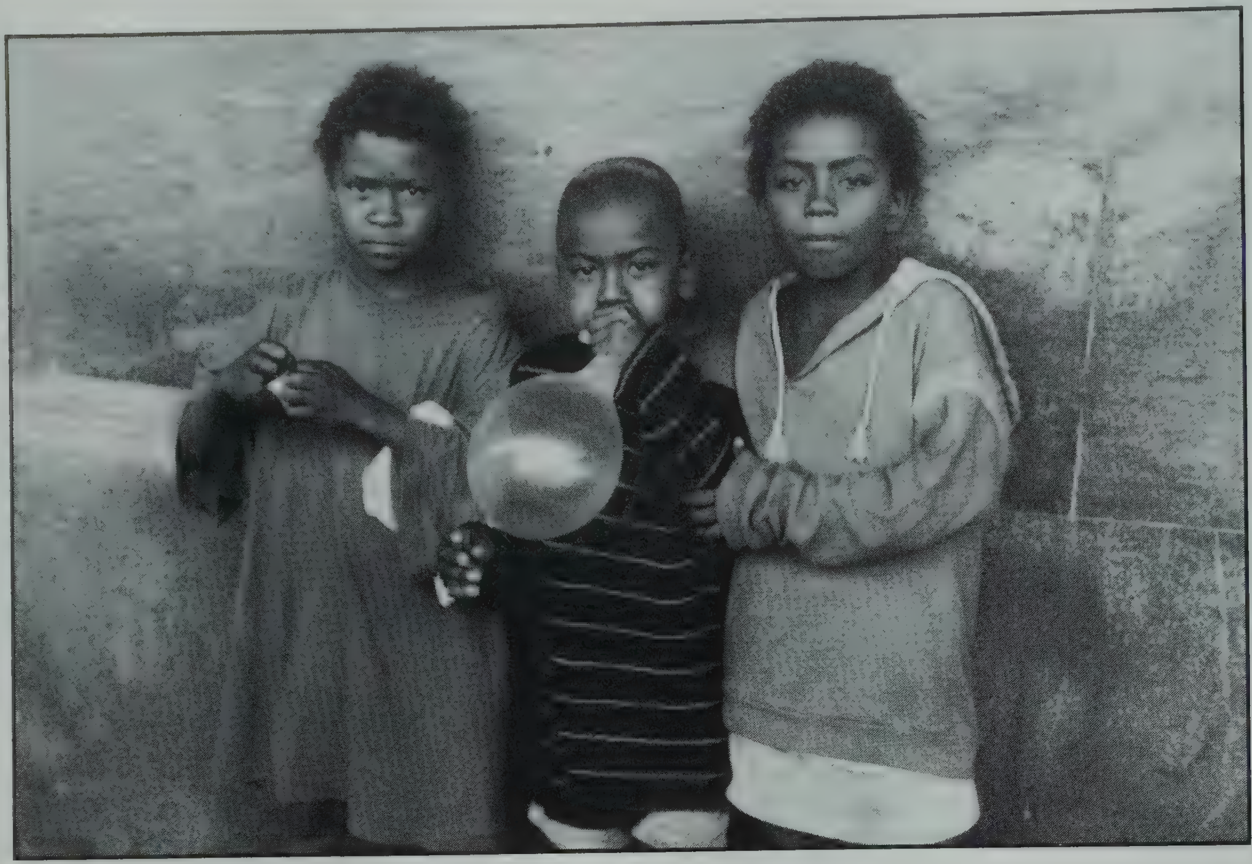
In the most affected cities, the changes in the social fabric are often harder to see, but are there nonetheless. Economic pressures on families increase as parents fall sick and die. Children drop out of school and often look for ways to survive on the street, where they face high risks of HIV infection and other dangers.

When they first envision the impact of the AIDS pandemic, most laymen and policy makers think immediately of the tragic effects of AIDS mortality in terms of the children who will be orphaned by the premature deaths of their parents. In truth, AIDS affects children in many ways. There are millions of children who fall into one or more of the following categories:

- children with the disease;
- children whose parents are sick or have died of AIDS;
- children whose siblings, relatives or friends have the disease or have died;
- children whose households are stressed by children from another family who have been orphaned by AIDS; and
- children, such as those on the street, who are at high risk of infection.

The children most directly affected by AIDS are those with the disease. The great majority of people with AIDS are adults, but because HIV can be transmitted

*Definitions of the term "orphan" vary considerably between different cultural settings. In this document, unless otherwise stated and in keeping with the Convention on the Rights of the Child, "orphan" refers to a child under age 18 either or both of whose parents have died.



from mother to child during pregnancy, birth or breastfeeding, there are substantial numbers of children who become infected. On average, one third of infants with infected mothers will themselves have the virus. Infected infants generally develop AIDS much more rapidly than do adults. An HIV–infected infant frequently begins to develop AIDS symptoms by six months of age. It has been estimated that globally about half of the children infected at birth die before age two. By age five, approximately 80% will have died,[1] though there is growing evidence that with good nutrition and health care some children are surviving considerably longer.

Worldwide, 100 million children are living on the streets. Their precarious existence makes them particularly vulnerable to AIDS.

While the problem of young children's being orphaned by AIDS has been most striking in sub-Saharan Africa, it is emerging elsewhere and within a few years will need urgent attention in most countries. The World Health Organization (WHO) has estimated that as of late 1993 about 2.5 million children had lost one or both parents to AIDS. As many as 5 to 10 million children under 10 years of age will be orphaned by the end of the 1990s as a result of the AIDS–related deaths of their mothers or of both parents, with 90% of these children being in Africa.[2] (See Annex I for predictions for specific countries discussed in this document.) The African proportion will decrease as the numbers of adults becoming infected and dying in other parts of the world increases. By the latter part of the 1990s, WHO projects that new HIV infections in Asia will exceed those in Africa. HIV is now spreading at an alarming rate in parts of Latin America as well.

The problems experienced by children

The communities most affected by the pandemic are struggling with unprecedented challenges to their children's well-being and survival as well as to their own viability. The problems children experience, whether in rural or urban areas, tend to fall into five broad categories. These are listed in Table 1.

Children's problems start long before a parent dies of AIDS. With a parent's illness, family income falls and resources are diverted to medications and treatment. The child becomes aware that the sick parent will die. Fearfully, the child

begins to wonder (because in many cultures such things cannot be spoken of), "What will happen to me when my parent dies; how will we live; how can I get the money to stay in school?" In households in which one parent is infected with HIV, the other often is as well. Children typically experience a long period of losing their parents, increasing economic hardship and growing uncertainty about their own future.

The precarious existence of the more than 100 million street children around the world leaves them highly vulnerable to HIV infection and intensifies most of the problems described above.[3] The threat they face from HIV infection, however, is much less immediate than other basic realities of their everyday lives. This reduces their concerns about HIV infection, thereby increasing their vulnerability to it. The overwhelming majority of street children do informal work during the day and return to their families at night. While having a family is generally an advantage for a child, those whom poverty has forced onto the street can count on receiving little in the way of material security from them. The pandemic is also pushing increasing numbers of orphans onto the street with no other way to survive than to work, beg or steal. Those living on the street without family or community support are at extreme risk; some are forced to prostitute themselves in order to survive.

Other epidemics and disasters also cause death on a large scale and leave orphaned children, but the pattern of HIV/AIDS is unique. AIDS is a protracted problem, which does not allow the prospects of a return to normality. Those who

Table 1. Problem areas for children whose families are affected by HIV/AIDS

Subsistence	Illness and loss of a parent may reduce the capacity of families to provide for their own needs, in rural areas to produce crops and in urban and rural areas to generate income.
Health	Increasing poverty causes a degradation of the family's immediate environment, multiplies health risks and reduces its ability to obtain health services. Vulnerability to HIV infection of children on the street is often very high.
Psychosocial well-being and development	The illness and loss of a parent is very traumatic for a child. The loss of consistent nurture can have serious developmental effects.
Shelter	Lost income or inability to repair and maintain the home can result in shelter being lost or becoming inadequate.
Education and training	Resources may be lacking for children to continue in school or with formal training. Traditional skills may not be passed on.
Inheritance	In some instances, land, home and possessions may be taken by relatives, leaving children homeless and with no protection from inheritance laws.

should be caring and providing for children and the elderly are the ones who are dying. In the communities hardest hit, there are fewer and fewer able-bodied adults to produce crops or income or to care for children, who are often pushed into poverty. The survival of those already poor becomes even more precarious. The problems are further exacerbated by the fear and stigma of AIDS which make other members of the community unwilling to help.

Influence of the contextual factors

At the level of individual children and families, the kinds of problems listed above generate tremendous personal suffering. When these problems become concentrated within a community, resources are stretched thin, the risks to individuals are intensified and the viability of the community itself may be in jeopardy. The contextual factors described in the following paragraphs have an influence on whether the kinds of problems suggested above become social problems affecting children and families on a large scale and, if so, who is affected and in what ways. Identifying and analysing these factors is a crucial step in designing programmes to respond to the needs of affected children and families.

The epidemiological pattern of HIV/AIDS is a key factor influencing which communities, children and families will be affected. Children are most vulnerable in countries where heterosexual contact is a major means of HIV transmission, as is overwhelmingly the case in sub-Saharan Africa and in South-East Asia and Latin America. Depending on the specific history of the epidemic within a particular country, certain areas will have higher prevalence rates than others. HIV prevalence is generally much higher in urban areas than in rural areas, and the difference is very large in some countries.

The demographic patterns in a society will influence the kinds of problems AIDS–affected children and families experience. Family structure is particularly significant. Extended families generally have more options for coping than nuclear families, while single parent families are especially vulnerable. The existing dependency ratio, i.e., the proportion of children and elderly in relation to adults of working age, is important because AIDS mortality will increase the burden on surviving adults. Similarly, the proportion of children in a community who are already orphaned from other causes will affect the community's capacity to provide for an increasing number of children whose parents die from AIDS.

Economic patterns and conditions can significantly affect the course of the epidemic as well as the capacity to cope with the effects of AIDS. Work-related travel often facilitates the spread of HIV infection. The impact of the epidemic on different economic systems—at the family, community or national level—varies considerably. In urban areas, the loss of a single wage earner can affect a large group of extended family members. Labour-intensive farming systems are more vulnerable to the loss of able-bodied adults than those that require less intensive inputs.

The effects of loss of labour on a community's ability to feed itself vary depending upon whether cultivation is done by hoe, animal-drawn plough or tractor.

Social and cultural patterns and norms affect what the sexual networks of those communities will be and, consequently, who becomes infected. Cultural beliefs affect understanding of how diseases are transmitted and avoided as well as the response to those who are seen to be ill because they have violated a social norm. Cultural patterns strongly affect understanding about who is responsible for the care of an orphaned child.

Knowledge about HIV/AIDS and attitudes towards people with AIDS also affect the willingness of a community to provide for the needs of those who are affected by the pandemic. In addition to their fear of the disease, people may discriminate against HIV–positive people because they associate their condition with behaviours of which they disapprove. In many places, fear and stigmatization have left HIV–positive infants—and sometimes children orphaned by AIDS—without care.

The access to services for children has a major impact on the welfare of those affected by the pandemic. Where subsidized health services are insufficient, families divert significant resources to treat the illnesses of infected members. Where children must pay school costs, those who lose their parents may be forced to drop out of school. The availability and quality of child welfare services to place and ensure care for children without families vary considerably among and within countries.

Laws and policies profoundly influence whether there is an enabling environment for addressing AIDS–related problems. They can protect the rights of those with HIV regarding employment, housing and health care. Inheritance laws, formal or traditional, can safeguard or disenfranchise widows and children. Government policy leadership can be important in reducing stigma and promoting appropriate responses to the needs of children and families.

Programmes for children affected by AIDS

There are no ideal responses to the needs of children whose parents have died, only better and worse ways to compensate for what has been lost and to promote recovery. There are no easy ways to protect the millions of street children around the world from HIV infection. Enormous and unprecedented child welfare needs are being created by the AIDS pandemic. Previous models for responding to the needs of children orphaned by war or disasters may be instructive, but they have not been designed to deal with the particular problems generated by the AIDS pandemic—notably, the fear and stigma of the disease, the long period of chronic illness prior to death and the high probability that a child will lose both mother and father.

The programmes described in the following section have shown themselves to be responsive to at least some of the needs of children affected by AIDS, but they are not presented as models that can be exactly replicated in other situations. Each has developed within a particular constellation of conditions, problems and resources.

However, they are addressing certain of children's needs and, as pioneering efforts, offer valuable lessons that may be applicable elsewhere. Some of the programmes described are relatively small and operate with very limited resources. This enhances their sustainability but limits their impact. In a few years, there are likely to be additional examples, but for now there is much that can be learned from these efforts.

Between September and November 1993, WHO and UNICEF sent a two-person team to review programmes addressing the needs of children affected by AIDS. They visited Uganda, Zambia, Kenya, Rwanda, the Dominican Republic, Thailand and the United Kingdom. They talked to people involved with AIDS at all levels—children who had lost their parents, infected mothers and fathers anticipating the crisis their children will face, staff and volunteers of relevant programmes and concerned government officials.

The main focus was on the programmes themselves, which ranged from tiny grass-roots initiatives to development activities covering large areas and thousands of people. Because each programme has evolved in response to a particular set of circumstances, information was also gathered on the different contexts in which they are operating. Programmes were selected to represent:

- both NGO and government responses;
- urban and rural settings;
- international geographic and cultural diversity; and
- a variety of affiliations and sponsors.

The types and locations of programmes reviewed and described are listed in Table 2. In describing these programmes and activities, the objectives of the study were to:

- increase awareness of the ways in which children are being affected by the pandemic and how these effects vary in different cultural and socio-economic contexts;
- through careful examination of a variety of initiatives/activities, identify the key ingredients of success—what seems to work;
- stimulate planning and action by governments and non-governmental organizations to meet the needs of children affected by HIV/AIDS; and
- provide a basis for advocating responsible policies, plans and programmes for affected children.

Table 2. Types and locations of programmes

Programmes in which the community's traditional coping mechanisms have been reinforced	Uganda, Zambia, Thailand
A programme that coordinates activities among all those assisting AIDS-affected children	Uganda
A programme among street children	Kenya
Children's homes	Kenya, Thailand
Foster and surrogate family care	Rwanda, United Kingdom
Programmes that cater for the needs of children during the parents' illness	United Kingdom, Dominican Republic, Thailand

In the report that follows, some names have been changed in the interest of confidentiality. A pseudonym is presented in quotation marks the first time it is used.

The inclusion of a programme in this document is not an implicit recommendation of its approach by WHO or UNICEF. The intention is to describe what is currently being done in the field, and to draw lessons from the strengths and weaknesses apparent in each approach.

UGANDA

Background

Statistical profile	
Total population (1992)	18.7 million
Children under 16 years (1992)	9.5 million
Population growth rate (1980–1992)	2.9%
Population in absolute poverty	Data not available
Population urbanized (1992)	12%
Annual average growth rate of urban population (1980–1992)	5.4%
GNP per capita (1991)	US$170
Average annual growth rate of GNP per capita (1980–1991)	3.3%
Infant mortality rate (1992)	111/1,000
Daily per capita calorie intake as percentage of requirements (1988–1990)	93%
Primary school enrolment (gross)* (1986–1991)	Boys—76%; girls—63%
Secondary school enrolment (gross) (1986–1991)	Boys—16%; girls—8%

The State of the World's Children 1994, UNICEF

Socio-economic and cultural context

Uganda is a country of potential, with good soil and a favourable climate. It is also a country that suffered chronic social and political strife, frequent armed

*Includes children repeating classes and/or out of age range

conflict and the devastation of government services through the 1970s and 1980s. Many thousands of Ugandans were killed by fighting or political murder during these years, leaving large numbers of orphans and widows. In 1986, the National Resistance Movement of President Yoweri Museveni came to power and began a physical, social and political rebuilding process.

President Museveni inherited a country with a wrecked economy, the basis of which is agriculture. Structural adjustment policies have enabled the Government drastically to reduce inflation, from 200% to 25% between 1988 and 1991, and to lay foundations for more effective government services. These changes have come, however, at a serious cost to families and children. Many small businesses have failed in the wake of vigorous government efforts to collect taxes. Large numbers of government employees have lost their jobs, and often their housing, as a result of cutbacks intended to reduce the civil service by about a third by 1994.

Extended family connections tend to be strong, and people in urban areas generally maintain close links to rural villages. This is particularly important with regard to the care of orphans. In most tribes, children who lose both their parents are traditionally taken in by their father's relatives, often in a rural area. Even though HIV prevalence is highest in cities and towns, it tends to be the villages that bear the primary burden of caring for the growing numbers of children orphaned by AIDS.

Households tend to be large, with an average size of between five and six persons.[4] The 1991 census found that over 1 million Ugandan children had lost one or both parents to all causes. This represents 11.6 % of the country's population below 18 years of age.[5]

The relatively small numbers of children living in institutions or without adult care, either in rural villages or on the street, suggest that the extended family is providing some level of care for the growing numbers of children orphaned by the epidemic. A recent Save the Children survey found that in the entire country there were 2,882 children living in institutions, less than 0.3% of the country's total number of orphaned children. A baseline survey carried out by World Vision found that even in districts like Rakai, which are heavily affected by HIV/AIDS, the percentage of orphaned children living without an adult in the home was about 2%.

The numbers of street children are also still relatively small, although they have increased in the last year. While about 4,000 children may be "on the street" during the day in Kampala, most return to a family at night. Less than 500 are thought to be living exclusively on the street. Local organizations working with street children, like Friends of Children and the Africa Foundation, see some whose parents have died of AIDS, but relatively few.

The AIDS epidemic

Some of the first AIDS cases in Africa were identified in 1982 on the northwestern shore of Lake Victoria in what is now Uganda's Rakai District. The roads that run through this area carry the commercial transport between Kenya, Uganda, Tanzania, Rwanda and Zaire, and it was along these routes that the epidemic apparently began its spread in East Africa. In addition to the lake area, HIV rates and AIDS deaths are relatively high in the northern parts of the country, where civil conflict and banditry have caused significant population displacement and social disruption. While infection rates are higher in these areas, no district in the country has been spared by the epidemic. AIDS has become the leading cause of adult deaths in Uganda.

HIV prevalence rates among adults in urban areas are high, up to 30% at some surveillance sites. While rates in rural areas tend to be lower, in the 5–12% range, they still reflect considerable spread of the virus.[6] In rural areas close to the lake, the effects of the epidemic are starkly obvious from the banana plantations going fallow, the houses closed or abandoned, the funeral processions on the roads and the recent graves near homes where grandparents care for children whose parents have died. Coffin making is a booming industry.

The Ministry of Health estimates that there were 315,000 cumulative AIDS cases as of the end of 1993. An estimated 1.5 million of Uganda's 19.9 million citizens are thought to be infected with HIV. All ages, rich and poor, in rural as well as urban areas, risk infection. Likewise, no ethnic or religious groups have been spared.[7] Hardly a family remains untouched by the epidemic.

HIV continues to spread. There is a high degree of awareness among adult Ugandans on how HIV is transmitted, and there are some indications that people are trying to change their behaviour to protect themselves. Mulago Hospital in Kampala, for example, has seen a dramatic decline in sexually transmitted diseases (STDs), suggesting an increase in condom use in the population served and/or fewer partners.

Reflecting their traditionally subservient role in Ugandan society as well as their high degree of physical vulnerability to HIV infection, young women and girls have been disproportionately infected by the virus. Officials of the Ministry of Health said that of the AIDS cases reported in the 15–21 age group, there were six times as many women as men. Sexual activity begins early for many young people, especially girls, in Uganda.

As a result of the epidemic, Uganda is experiencing a slow onset disaster of major proportions. Work is under way to try to measure its demographic impact and to project what its socio-economic consequences may be. Despite years of armed conflict and social disruption prior to the emergence of the epidemic, Ugandans have responded with courage and compassion to combat the spread of

HIV, responding to the needs of those with AIDS and caring for the children orphaned by the disease.

While it is impossible to know how many children have lost parents to the disease, one projection put the figure in the range of 120,000 per year. The plight of orphaned children on their own or in the care of elderly grandparents is one of the effects that has been painfully apparent and that has prompted both significant local responses as well as international attention and aid.

Child welfare services and policies

For administrative purposes, Uganda has ten regions divided into 39 districts. At the top of the political and administrative tree is the National Resistance Council, the country's parliament. Local government is administered by Resistance Committees down to the village level. Theoretically, the various ministries of central government should have staff at the district level, but money for salaries is short and few ministries do have staff actively working at the local level.

Prime responsibility for the welfare of children rests with the Ministry of Labour and Social Affairs. In the decentralization process, responsibility for child welfare is vested in the vice-chairperson of the Resistance Committees right down to the village level.

With the support of UNICEF, the Ministry of Labour and Social Affairs is putting in place a national system of orphan registers that will be maintained at the village level and provide an invaluable tool for monitoring changing patterns regarding locations and care arrangements for orphans, as well as identifying areas needing priority attention.

The Ministry recently elaborated new child welfare policies and drew up a plan of action. The guiding principle of the plan is that the best place for children to be brought up is within the family and that when a child has to be placed in an institution for any reason this should be a temporary arrangement while a family home is being found.

In August 1990, Uganda ratified the Convention on the Rights of the Child. In October of that year, a Committee was set up to review all laws concerning children, and its recommendations—in line with the Convention—are at present before the Ugandan parliament.

The new law would create a favourable environment and give judicial backing to enlightened policies and programmes for children's welfare. However, scarcity of resources and professional skills are huge constraints at present. Furthermore, according to professionals in the field, much work needs to be done to sensitize the public and the police.

The Uganda Community-Based Association for Child Welfare (UCOBAC)

As programmes to help AIDS orphans mushroomed in Rakai, the need for some sort of mechanism to coordinate their activities became apparent. UNICEF strongly advocated the formation of a body through which this could be done. The Uganda Community-Based Association for Child Welfare (UCOBAC) was the answer. Formally established in October 1990, it is a consortium of organizations, government departments and individuals working in the field of child welfare in the country. Its major objectives are to:

- foster collaboration among all the players in the field: NGOs, government and donors;
- strengthen the capacity of local communities to plan and obtain resources that will improve the circumstances of their children;
- strengthen the capacity of NGOs in management, planning and implementation;
- provide constructive input to government policy formulation; and
- define vulnerable children and identify their needs and priorities for programmes, while building data collection and storage systems to assist in these activities.

UCOBAC has a small, Kampala-based secretariat consisting of a programme manager; officers for training, technical assistance and their grants bank; a data and information manager; an administrative assistant and five support personnel. Their offices are in a space provided by the Ministry of Labour and Social Affairs.

While UCOBAC has been influential at the national level, its importance to grass-roots organizations is even more significant. The organization has helped bring them into the same arena as major NGOs, donors and the Government. By 1993, local groups had come together in 34 of Uganda's 39 districts to form associations and affiliates with UCOBAC.

With an initial membership of 57 local and 17 international NGOs, 19 individuals and UNICEF as the sole donor, UCOBAC membership has grown to include 165 local and 10 international NGOs, 58 individuals and UNICEF, Save the Children Fund (UK), World Learning, the African Medical and Research Foundation, Kiira Adult Education and ActionAid as donors. The United Nations Development Programme, the Overseas Development Administration (of the Government of the UK) and WHO are each facilitating UCOBAC activities.

Guided by a 13-member Management Committee, UCOBAC has sub-committees for training, advocacy and communication, finance and district development. Following intensive debate, UCOBAC adopted an election mechanism for the management committee that ensures that each part of the country is represented,

that no district is overrepresented and that there is an equal balance of women and men. Its members are elected at a general meeting each October.

UCOBAC's 10-member District Development Sub-committee has the job of developing the district affiliate structure that links grass-roots organizations with the capital. Two members of the sub-committee together with one staff member from the secretariat make multiple visits to each district where there are at least five UCOBAC member groups interested in forming an affiliate. When they visit a district, the UCOBAC representatives listen to local concerns and priorities and explain the organization's purposes and the benefits of participation. They assess the capacity of a potential affiliate to function.

In some districts, the driving force behind coming together is concern over children being orphaned by AIDS. In others, the primary concern is the effects of years of armed conflict and social disruption. Street children are a major concern in some areas. In most cases, a district affiliate is given active support by the district-level officer of the Ministry of Labour and Social Affairs, facilitating collaboration between grass-roots organizations and the Government.

Establishing their own district-level association helps local organizations exchange information and coordinate their activities. Through the link to UCOBAC, they gain access to training, a voice in national policy development and opportunities to visit successful programmes in other parts of the country. They also are able to seek funding through the UCOBAC grants bank mechanism.

UCOBAC organizes residential training workshops in each newly affiliated district. Over a five-day period such programming tasks as needs assessment, project design and proposal writing are covered, as well as project implementation and monitoring. There is an overview of national legislation concerning children and basic child-care and protection issues. Government policy on community-based approaches to the needs of vulnerable children is stressed throughout.

The grants bank

The UCOBAC grants bank scheme bridges the gap between small, sometimes tiny, groups with the capacity to carry out low-cost grass-roots initiatives and major donors who have resources but are not structured to identify and screen such applicants. Funding does not actually pass through UCOBAC but goes directly to grantee organizations. This has avoided the expense of UCOBAC's maintaining financial management staff to handle the funds. UCOBAC's role as facilitator, however, makes such small grants possible.

When a donor is prepared to support grass-roots initiatives, UCOBAC helps define the criteria for funding and informs its district affiliates. With support from

the district officer from the Ministry of Labour and Social Affairs and other designated district officials, an affiliate does the initial screening of proposals. At the national level, representatives of UCOBAC, the donor and concerned ministries make the final selections. Funds are then transferred directly from the donor to the grantee. UCOBAC and the donor monitor results through regular joint visits to project sites.

The first funds started to flow to 12 grass-roots projects in 1992 with a US$32,000 allocation from UNICEF. The largest of these grants was US$4,181 to set up a maize mill, the proceeds of which are to help pay school expenses for 283 vulnerable children. The smallest was for US$167 to enable a women's group to grow passion fruit and produce honey to generate income to benefit 72 orphans and 18 foster parents.

In 1993, World Learning allocated US$75,000 to 15 small organizations in various parts of the country. In the same year, UNICEF channelled US$66,000 through the scheme, including US$35,000 to boost vocational training initiatives.

With the end of its long civil war, Uganda has faced the demobilization of much of its army and the need to reintegrate former soldiers into civilian life. As in armies elsewhere in the region, the HIV prevalence rate was found to be high. Anticipating the problems that will arise as AIDS begins to develop in these families, UNICEF allocated US$250,000 for projects to facilitate the community reintegration of female veterans and wives of veterans. UCOBAC is using its grants bank mechanism to allocate these funds because of the significant numbers of children it is anticipated will eventually be affected.

Advocacy and information exchange

UCOBAC's advocacy has been carried out, first, through promoting within its own membership sound, community-based approaches to the needs of vulnerable children. Second, at the national level it has gained recognition as a collective voice for NGO opinion. The organization contributed to the review of Uganda's laws in relation to the United Nations Convention on the Rights of the Child and participated in the development of the country's plan of action as called for by the World Summit for Children. UCOBAC is also a member of the Ministry of Labour and Social Affairs' National Council for Children.

With the support of WHO, UNICEF and the UK–based organization ActionAid, UCOBAC has produced *The Orphans Generation*, a video that has gained international attention. It describes the nature of the problems the AIDS epidemic is causing for children in Uganda and explains why the Government and NGOs are committed to addressing these problems by strengthening family and community capacity to care for vulnerable children. In addition, the organization has a radio

broadcast in five languages and publishes a newsletter, *The Vulnerable Child*, which provides a forum for members to exchange information and experience.

In the latter part of 1993, UCOBAC undertook jointly with the Ministry of Labour and Social Affairs a countrywide analysis of the situation of vulnerable children, with a particular focus on orphans. The study seeks to quantify the problem and project how the number of orphans will change as the epidemic evolves. Through extensive use of focus groups, the research also looks at how the situation of orphans varies at the family and community levels in different parts of the country.

UCOBAC has helped organize a series of exchange visits between organizations working in the Rakai District and groups working with AIDS–affected children across the border in the Kagera region of Tanzania. These visits have provided insights on both sides of the border. The Tanzanian model of child care and nutrition centres has been used in Rakai, and the Ugandan orphans enumeration system has been adopted in Kagera. The value of having a body like UCOBAC was quickly recognized by the Tanzanian NGOs. In 1991, they formed the Kagera Community-Based Organization for Child Welfare (KACOBAC), which has objectives similar to those of its Ugandan counterpart.

Funding

UCOBAC's 1993 budget totalled approximately US$176,000. Since the beginning, UNICEF has provided the core funding for the administrative structure as well as funding through the grants bank. Support for operating costs also comes from dues paid by the organizations and individuals who join. In 1993, the US–based organization World Learning provided funding for a technical assistance officer, a vehicle and staff training. The African Medical Research Foundation provided funds for training member groups.

Rakai District

The epicentre of the epidemic in Uganda, Rakai has been the location of some of the most significant initiatives launched anywhere in the world to address the effects of AIDS on children and families. Several of these are described below. While some are large-scale programmes (see section on World Vision), most are small local initiatives organized by people who are trying to help their neighbours and themselves cope with the unfolding disaster of AIDS (see section on grass-roots initiatives).

Rakai is a rural district with a few small towns and a total population of just over 383,000. The Baganda are the predominant ethnic group, making up more

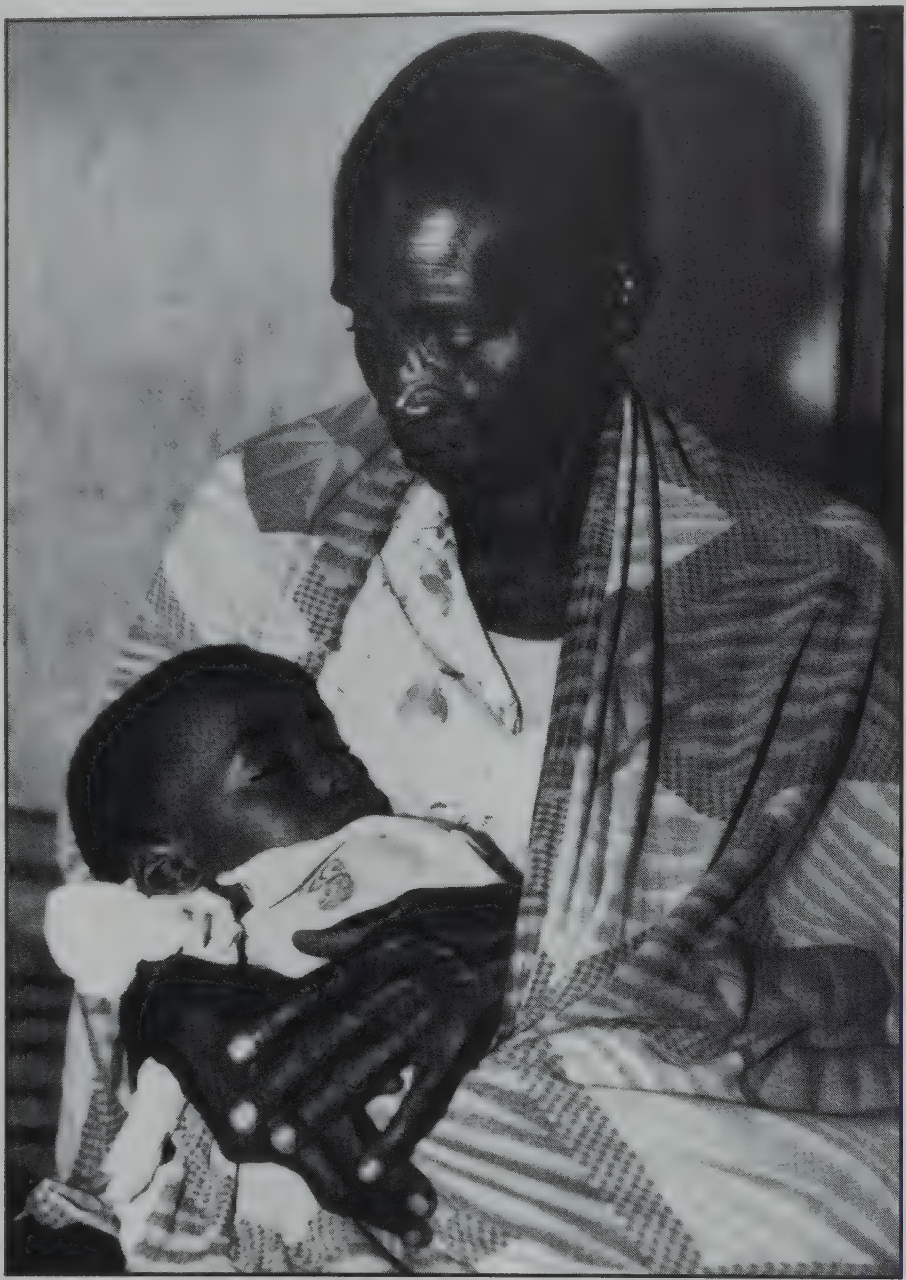
than two thirds of the population. About 60% of the residents are Roman Catholic, 30% belong to the Church of Uganda and 9% are Muslim.[8] Rakai has some of the most fertile land in Uganda and plentiful and consistent rainfall. Matooke (a plantain) is the traditional staple crop. Family plots are generally small, under three acres. Crop production, however, has been affected by ongoing problems with a banana weevil blight and, in 1991–1992, by an uncharacteristic drought. Recent research found that there has been substantial reduction in the amount of land under cultivation, with sickness and death of family members being the primary causes. The types and quantity of food produced have also declined.[9]

Because AIDS was identified early in this district, it has been the site of ongoing research on the spread of the epidemic. One such initiative is the Rakai Project. Started in 1988, it is a joint project of researchers from Uganda's Makerere University, the national AIDS Control Programme and Columbia University in the United States. They have found a wide range in the rates of HIV infection within the district, from as high as 50% of those tested in some trading centres to as low as 2% in some rural villages (those in the sample groups are 13 years of age and above). The sample in those communities they classified as trading centres had an average prevalence rate of 35%, while the average rate in rural villages was found to be between 9% and 10%.[10] Knowledge about AIDS is high among district residents, but condom use is not. In 1991, only 5% of the research project's sample group of over 7,000 had ever used a condom.

To provide a basis for planning responses to the emerging crisis, Save the Children Fund (UK), with the Ugandan Government, carried out an enumeration of orphans in Rakai and three other districts in 1989. The revelation that there were over 25,000 orphans in Rakai alone (12.8% of all children in the district under 18 years of age) gave weight to the argument in favour of a community-based approach. Quite apart from cultural considerations, institutional care was quite simply unaffordable. Publication of this study in 1990 ("Orphans as a window on the AIDS epidemic in sub-Saharan Africa: initial results and implications of a study in Uganda"[11]) played a large role in raising the international community's awareness of the pandemic's effects on children.

The demographic impact of AIDS in Rakai is becoming apparent. The dependency ratio, calculated from 1991 census results, was 10% higher for the district than for the country as a whole. A survey carried out by World Vision in Rakai to provide a basis for planning their programme in the district found that 22% of the heads of family caring for orphans were age 60 and above; 2% were 18 years or less.

Uganda's 1991 census found that there were over 38,000 children in the district who had lost one or both parents from any cause. This represents 17.9% of all children under the age of 18. Both the 1969 census of Uganda (before war and AIDS) and 1991 census findings from a district in the same part of Uganda little affected by AIDS or armed conflict indicate that about 10% of children have lost one or both parents.[12] If this reflects a pre-AIDS baseline, it would mean that in



In the areas of the world most hit by the AIDS epidemic, grandparents are increasingly left to care for their grandchildren orphaned by AIDS.

1991, around 8% of the children in Rakai had lost a parent to AIDS—this represents about 17,000 children.

The particular problems of children orphaned by AIDS began to be apparent in Rakai as early as 1988. Concern for the growing numbers of youngsters in the care of elderly grandparents prompted initiation of a variety of programmes. At the same time, international news coverage drew the attention of the outside world to this emerging pattern and foreign NGOs and donated funds moved into Rakai. There was intense debate about how best to respond. Some organizations, recognizing the weakening of the extended family as a result of urbanization and the epidemic, encouraged the establishment of child-care institutions. Others stressed the fact that such an approach was alien to the cultural traditions of Uganda's people and advocated community-based care that would strengthen families and communities.

The debate over institutions was resolved in early 1991, and the Government issued policy guidance in favour of community-based responses to the needs of vulnerable children. Orphanages were to be discouraged and existing institutions would have to meet stringent standards for care. This policy leadership has helped guide the activities of NGOs. The wisdom of the direction taken was reinforced through a national conference in 1992 called "Managing Uganda's orphans crisis".

The rapid proliferation in Rakai of NGO and grass-roots efforts to help orphans generated territorial battles and a need for coordination. In 1991, the Rakai Joint Advisory and Welfare Council (RAJAWC) was formed. With 50 members, it meets monthly to share information, ideas, expertise and resources. Several ministries, as well as private organizations, participate. Its affiliation with UCOBAC links the group to other districts and to national-level discussions.

RAJAWC is supported by a team of four social workers with the district office of the Ministry of Labour and Social Affairs. This group sees itself as the right hand of NGOs working in the district. Recognizing that voluntary agencies have limited power, the team is able to give their efforts constitutional and legal backing. This supportive relationship is two-way. The team's efforts to promote sound child welfare initiatives are possible largely because of the support they receive from Save the Children Fund in the form of vehicle, fuel and salary supplements.

Grass-roots initiatives in Rakai

As the extended family system has been progressively weakened by the increasing numbers of orphans, communities have found ways to provide for children's immediate needs and to help orphans prepare to support themselves in the future. *Munno mukabi* ("friend in need") women's self-help groups are common in Baganda villages, usually for providing mutual support with the tasks that need to be done during weddings and funerals. This tradition of collective effort has provided a base on which many small but significant voluntary efforts to help vulnerable children have developed in Rakai. Other community initiatives in the district are more formally structured as NGO programmes. Both types are included in the four examples below.

Basoka Kwavula

Kifunta village has been heavily affected by AIDS. Early in 1989, women of the village decided to do something together to help meet children's needs and to reduce their own burden. Calling themselves *Basoka Kwavula* ("before you walk, you crawl"), they decided to start a day-care programme for children who could not afford to attend school. Using a community building, the programme included 120 children. Through the sale of handicrafts, the group tried to raise money for such items as food, medicine and soap needed by children in the village, but this proved fairly labour intensive and produced only a little income.

In 1990, when World Vision began its programme to assist vulnerable children in Rakai, its staff established a working relationship with the women of *Basoka Kwavula*. World Vision was able to pay the school fees of most of the children in the day-care programme which enabled additional, younger children to take their places. To provide another way to raise funds, World Vision cleared and ploughed some available land so that passion fruit and other crops could be grown for market, as well as cassava for distribution to children in need.

In September 1993 almost all of the 30 members were caring for orphaned children in their own homes. Ten had lost husbands to AIDS and feared they might be infected themselves. But a well-justified pride shows in the faces of the women of *Basoka Kwavula*. It reflects both what they have been able to do as well as how they have, themselves, changed in the process. As one of the members said, "Our lives are different because we have come to know each other." The group meets every week to talk about their activities and for fun. Some have learned to play drums and others to sing. They sing about the realities of their lives. Their songs are often about what AIDS is doing to their families and community. In the face of loss and fear, the solidarity they experience in the group is a source of hope.

Rakai Foster Parents

A boy of 14 years with sad eyes sits on the edge of a bed in a dimly lit, almost bare hospital room at the edge of Kyotera town. He is recovering from malaria and

pneumonia, but is much better and will be able to go home soon. That will mean resuming his responsibilities as the head of his family, which includes two younger brothers. Their parents died of AIDS, and because of a quarrel in the family their grandmother does not visit them.

The members of the Rakai Foster Parents group help look after the boys. The group will pay for the hospital stay and ensure that the boys have something to eat. In 1989, with the support of Rakai's district administrator, a small group of residents in the Kyotera area initiated Rakai Foster Parents. With a membership of 11 women and 2 Catholic brothers, they are assisting seven groups of orphaned children and have started a programme to teach traditional weaving skills to young people who have had to drop out of school.

They are assisting about 50 children with school fees and uniforms, books and supplies, medical care, accommodation and food. For one family of five young children who have lost both their parents, the group pays a young woman to provide daily care. The members have each committed themselves to visit weekly either this family or the one of three brothers. The group uses their own resources and donations to provide material assistance to the children.

They plan to provide ongoing support to the children through agricultural activities. In 1989, the group bought land in a village and have arranged for the use of another plot in Kyotera town. Altogether, they have over 20 acres. In 1993, they received a grant of US$2,900 through the UCOBAC grants bank to produce maize, beans, matooke and cassava as well as wood. Children who are to benefit helped with the planting and weeding. The group's initial effort in bee-keeping was frustrated when someone raided their hives and stole the honey, but they plan to try again. Their coordinator joked that the next time they might put the hives in the church where no one would dare to steal them.

The weaving programme takes place in a small rented storefront just off the highway in the town of Kyotera. Twenty-five trainees between 12 and 18 years of age learn to weave *gomesi*, a trim for traditional Ugandan dresses. Additional lessons are given in cooking, handicrafts and tailoring. As an incentive, trainees receive a bar of soap each week, which in a village is equivalent in value to a stalk of matooke that would feed a family for several days. With six months of training and a simple loom, they should be able to earn this much for about two days of work.

While the impact of the Rakai Foster Parents is limited in terms of the number of children reached, it is very significant to those they help. There are many other small-scale efforts like it in Uganda, groups of caring compassionate people who are doing what they can to reach out to the children in their communities, and collectively they are making a difference in the lives of many children.

Orphans Community-Based Organization

The Orphans Community-Based Organization (OCBO), a broad-based organization with members throughout the district, is another of the early local efforts in Rakai to respond to the needs created by the epidemic. Its efforts are district-wide, and it is more formally organized.

The enumeration carried out in 1989 by Save the Children Fund showed the importance of knowing the scope and locations of the orphan problem. OCBO was organized in 1990, initially to develop a register of all the orphaned children in Rakai. Initial donations came from journalists who had come to Rakai to cover the "AIDS orphans" story and from a grant from UNICEF. More recently the Danish International Development Agency (DANIDA) has provided funding to update the register on a monthly basis. Both World Vision and Concern, an Irish aid agency, used the initial register when they were planning their programmes in Rakai.

Maintaining the register is a labour-intensive task. In each of Rakai's 672 villages, OCBO has organized a committee responsible for registering orphans. There are 25 part-time fieldworkers who gather lists from villages and provide them to the 3 OCBO office staff members who compile and maintain the register. The register includes information on the head of each household caring for orphans that can be used to determine whether the proportion of households headed by children or elderly people is increasing as well as the numbers and locations of orphaned children. In September 1993, there were 38,919 orphans listed in the register.

Identification of orphans provided a basis for and quickly led OCBO into various kinds of assistance to vulnerable children. In 1993, using the membership dues of just over US$6 per year and donations, they were covering the costs of primary school participation for 318 children as well as supporting 11 senior secondary students and 1 medical student at the national university. The village OCBO committees identify the children most in need of school assistance and basic material support. Over US$17,000 donated by a German film crew has been used along with membership dues and other donations to meet immediate needs for food, household supplies, bedding and repair of homes.

OCBO's focus is not just on relief assistance for immediate needs, however. They are also addressing how vulnerable children will be able to support themselves in the future and how they can protect themselves from HIV infection. With funding from UNICEF through the UCOBAC grants bank, OCBO has arranged apprenticeships with local artisans for 136 out-of-school youth. In return for receiving tools from OCBO, 16 local artisans have agreed to take on as trainees groups of children identified by the village committees.

In Lyantonde town, for example, with her own sewing machine and two that OCBO has provided, a seamstress is teaching 12 girls basic tailoring on the porch of her cloth shop. As the trainees develop some skill, they help make school uniforms that are sold to generate income for the shop and themselves. Around the corner in a metal shop, five boys are learning how to make household items like stoves and lamps from scrap metal. Like other trainees placed by OCBO, both groups receive a lunch of porridge each of the six days per week they come for training. While OCBO's apprenticeship scheme depends initially upon the good will of local artisans, they may expect in the longer term to increase their profits as their trainees develop skills.

Another promising initiative of OCBO is an ox plough scheme. Common in northern Uganda, animal traction is not traditionally practised in Rakai, although cattle are raised there. Tilling the soil is normally done by hoe or, in some cases, by tractor. With the loss of adult labour due to AIDS, however, potentially productive land in the district is going fallow. OCBO has brought six oxen and a trainer from Karamoja in northern Uganda and has obtained four additional local oxen.

Concerned with the threat that HIV infection poses to the young people of Rakai, OCBO began organizing Youth AIDS Clubs in July 1993. Within three months, 10 clubs had been started. One of the main activities of the clubs is AIDS education through drama. Clubs were also engaged in income-generating projects.

Rudeser

Rural Development Services (Rudeser) is a local NGO established in 1984 to promote human, economic and social development in one sub-county of Rakai. Its founder studied development in Ireland and returned home hoping to help counter the urban migration of youth. By 1991, he and the Board of Rudeser decided that new approaches were needed because the people they were trying to attract to the land were the ones dying of AIDS. Rudeser has carried over the community-based, self-help orientation of its initial programme into the activities it has developed to address AIDS–related problems. Rudeser's staff includes a programme manager, a coordinator for vocational skills training, two nurses, a storekeeper who serves as secretary for their savings and credit association, a manager of their maize mill and four support staff.

With a grant of US$5,200 from Terre des Hommes, Lausanne, Rudeser operates a home-care and nursing programme for over 340 people with AIDS and their families. Those patients who can do so come to the programme's centre in Lwanda village for treatment. Twice a week the two nurses visit those who are housebound. In addition to medication and instruction on home care, the nurses are able to provide some basic food items to some of the families. They also help families plan for their future, with particular attention to how the children will support themselves. The nurses try to alleviate the emotional suffering of families and to "accompany our people to die with dignity."

This 15-year-old, who yearns to become a tailor, mends clothes for his 10 brothers and sisters. His father, who died of AIDS, left him his treadle sewing machine.

Since 1992, Rudeser has been assisting children from the families in the home-care programme to attend school. With a US$15,400 grant from Terre des Hommes, in 1993 they were assisting 144 children in primary school and 20 older youths in vocational school.

Rudeser is active in promoting participatory approaches to development. They have started a credit association and have a 100-hour course to promote more effective farming methods in which they include older brothers and sisters of children assisted with school. In 1993, they started a pig project. Six female piglets from their sow have been distributed to vulnerable children, each of whom is expected to give a piglet from their own first litter to another child in need.

With funding from UNICEF through the UCOBAC grants bank, Rudeser has also organized the same sort of apprenticeship training that OCBO and World Vision are carrying out, but with a wider range of skills. Most of the participants are in the 13–18 age range and are from the families assisted through the home-care programme. Rudeser has arranged for 16 artisans to provide training in brick making and masonry, carpentry, tailoring, metal work, pottery and the traditional skill of bark cloth making. There is poignancy to the fact that orphans are learning the latter skill. In addition to being worn as clothing on ceremonial occasions, bark cloth is used as a shroud for the dead, and AIDS is creating a market for it.

Rudeser's programme manager believes the apprenticeship approach to skills training is particularly valuable in Rakai. He stressed that the majority of children finish their formal education before secondary school and that they are only prepared to work for someone else. This only serves to encourage them to leave their villages for urban areas in search of jobs. Placement with artisans, however, not only conveys marketable technical skills but also provides practical experience in how a small business is run. This, he believes, will help them to become "job makers instead of job seekers." He anticipates that some of the trainees will stay with the artisans who have trained them and form production units and is discussing with a donor the need for a loan pool to capitalize those who complete their training.

One of the artisans participating in the programme runs a bicycle repair shop in a nearby village. He records the daily attendance of the eight boys placed with him and makes a home visit if one of them is absent for several days. Nursing a sick parent sometimes keeps his trainees at home, but attendance has generally been good. The chief concern he had about the programme was that the promised tools have not yet arrived due to a slow international procurement process. This limited what the trainees are able to do and learn. Taking on the trainees without having enough tools for them has reduced his income due to the time he must spend with instruction, but he expects this will change. He knows that what he is doing is important. He has lost 13 of his own children and is providing for 17 grandchildren in his own home.

World Vision's Orphan Programme in Rakai

World Vision—one of the world's largest voluntary aid agencies, based in the USA and with programmes in over 90 countries—began operating in Uganda in 1986. By 1993, it was supporting 76 development projects countrywide. Its programme of assistance to orphaned children came about as a result of an appeal in 1989 by the Ugandan Government for NGOs to put up proposals on how to deal with a problem that was becoming more serious by the day: years of civil war had left many children orphaned; now their numbers were being swelled by children whose parents were dying of AIDS.

The Government had already embarked on an extensive structural adjustment programme, with support from the World Bank, and was very concerned about the effects on the poorest Ugandans of the measures deemed necessary to rescue the failing economy. It had therefore convinced the Bank of the need for a parallel programme of poverty alleviation and secured a soft loan at an interest rate of 0.5% to finance the programme. It was looking for partners.

World Vision suggested adapting its existing community development programmes to focus more specifically on children and expanding its activities into areas where the AIDS problem was most acute—particularly Rakai and Masaka on the shores of Lake Victoria, and Gulu, bordering Sudan in the north of the country.

Essentially, World Vision's orphan assistance programmes in Rakai, Masaka and Gulu are designed to strengthen the economic and social fabric of whole communities so that they can carry the burden imposed by AIDS. Everyone in its programme areas is affected by AIDS in some way or another, and orphans are not the sole beneficiaries of the programmes.

In all its activities, World Vision collaborates closely with government structures and civil servants, including the Resistance Committees and local representatives of relevant ministries. This makes best use of scarce resources and avoids duplication of services. And—very importantly—it encourages sustainable development by forging working relationships between the community and state structures that will remain in place if and when World Vision moves on.

Before starting its programme in Rakai, World Vision commissioned a baseline survey on orphans and foster families in the district. The survey covered 590 households and revealed a picture of abject poverty, with families struggling with insufficient skills or resources to survive.

Selected findings were that:

- over half the households had 6–10 people living in them;
- 43% of all households were caring for 3–5 orphans, 18% were caring for 6–10 orphans, and 3% were caring for more than 10;
- one third of foster parents had no formal education at all, while nearly half had not completed primary school;
- 80% of foster parents described subsistence farming as their main occupation;
- the majority of homes were of mud or clay with thatched or tin roofs, and many were in need of repair or even in danger of collapsing;
- one fifth of homes had only one room for sleeping;
- the majority of families could not afford decent clothing or sufficient bedding for their members.

The survey concluded that "the extended family, though a commendable option for the care of children, is currently too weak to secure the future of orphans."

Not surprisingly, when World Vision set up office in Rakai in 1990, it found the community on the edge of despair. So many families were nursing sick members and so many had already died that the survivors felt overwhelmed. "They didn't think they could do anything," said the manager of the Rakai programme, which operates out of an office in the small market town of Kyotera. "We got the Resistance Committees to gather the people together, and we gave group counselling to wake them up to take responsibility for the kids."

Sharing people's lives and daily risks by locating its offices in the community it serves has been crucial for the credibility of World Vision's staff and for building up trust.

Staff at the Rakai office in Kyotera include:

- a technical team, consisting of specialists in agriculture, health, and enterprise development. They are essentially trainers, responsible for upgrading or passing on skills to the community. The job of the enterprise development officer, for example, is to help individuals and groups in the community to identify and develop feasible small enterprises and to give them the business skills necessary to run them.
- a credit counsellor, so-called because he is dealing with people who have little or no experience in borrowing and who need regular, non-judgemental advice.
- a "correspondence analyst" responsible for a limited programme of child sponsorship.

The Kyotera office is responsible for a network of five smaller field offices at the community level known as Development Assistance Centres (DACs). Each centre is run by a coordinator who works out of a small building donated by the local government, or rented in the community, or even out of a room in his or her own home.

The coordinator is responsible for a team of Parish Counselling and Development Workers, known as PCDWs. These people are selected by the community and trained and paid by World Vision, which stipulates that at least half these workers must be women. There are 34 such workers in Rakai, and they are the direct link between the programme and beneficiary households. They are also responsible for monitoring orphan care in the parish.

Working with AIDS–affected families can be stressful. In the first eight months of 1993 alone, 1,179 people died, leaving 1,507 children in 29 parishes covered by the programme. All World Vision field staff are trained in counselling and are involved daily in helping families prepare for and come to terms with death. The organization recognizes the very real dangers of "burn out". Roughly every three months field staff go on retreat, allowing them to recover their emotional and spiritual strength away from their normal working environment.

Besides its salaried staff, the Rakai programme—which covers some 330 villages of 100–200 households each—has a network of over 1,500 volunteers. The volunteers are organized into "orphan care committees" of at least five members, a high proportion of whom must be women. Among other things, the orphan care committees' tasks are to identify potential beneficiaries, and they work closely with the PCDWs.

The volunteers all receive regular training from World Vision's technical staff—often working alongside local government officials—at frequent community-level seminars. These cover a wide range of development issues, from health and hygiene to nutrition and legal issues.

With the daily struggle to survive in Rakai, what is the incentive to volunteer? "Everyone here is looking after orphaned children for brothers and sisters who have died," said a member of the Bisanje Parish orphan care committee in Rakai. "Some of us have as many as five or nine. It's a problem we all live with."

All at the gathering agreed that their work was hard but fulfilling, saying that they had seen real changes in village life as a result of their advocacy. People now boil drinking water, and the incidence of diarrhoea has diminished. Immunization rates have increased; women are more active in the community; and people's diets have improved with the addition of green vegetables to the regular menu. But most importantly, they said, people are beginning to feel that the programme is their own and that they have the power to improve their own lives.

Programme activities

a) Education

In theory, primary education in Uganda is affordable, but in practice it is not. Parents are faced with a Parent Teacher Association (PTA) fee that varies from district to district (and sometimes from school to school), as well as the costs of uniforms and scholastic materials. In 1993, primary schooling in most of Rakai cost about US$11 per child per year for the PTA fee alone. At nearly one tenth of the average annual earnings per person, this sum is beyond the means of many families, especially those with orphans.

Working on the principle that straight hand-outs encourage dependency and should be avoided wherever possible, World Vision's education support scheme is run on a cost-sharing basis. While the organization pays just over half the PTA fee for a child, the parents or foster parents are expected to pay the rest. Only in exceptional circumstances, such as when children are surviving on their own, does World Vision pay the full cost of education, including uniforms and school equipment. But lack of money for fees is not the only barrier to education in Rakai. The local community is responsible for the provision and upkeep of school buildings to which the Government then appoints teachers. In Rakai, so many adults have died of AIDS that there is an acute labour shortage. In some villages, old schools stand empty for want of repair, while new buildings that have been started have been abandoned half way through construction. World Vision's education programme therefore includes rehabilitation and construction of schools. This, too, depends on partnership with the local people, who usually provide the labour and some building materials while World Vision provides the rest. The aim of the school building programme is always to erect as quickly as possible something in which classes can begin while the building is being finished.

World Vision's education programme in Rakai has had remarkable results, exemplified by the case of Kyotera Township Primary School. At this major pri-

mary school, attendance had dropped from its normal level of 190 pupils to just 60 by 1991 because so many children in its catchment area had been orphaned and could no longer afford education. Construction of new classrooms by local parents had stopped, too, as many of the people involved had died.

When World Vision entered the picture, a group of determined women—many of them widowed by AIDS—were still making bricks, but there was no one skilled or strong enough to continue building. The organization undertook to provide the labour and the rest of the building materials, and began supporting pupils who could not afford school. By 1993, attendance had risen to 250 pupils, of whom 210 were orphans, and all the classrooms were up, though completion of the building was awaiting delivery of cement.

Already by the end of 1992, enrolment in the 76 primary schools in World Vision's project area had risen by 233%.

b) Vocational training

World Vision's vocational training programme is designed to give older children skills with which they can earn a living. There are three approaches. In one, youngsters are sponsored by World Vision to attend technical centres in the area. A second option is for trainees to attend technical centres set up by World Vision, often in out-buildings of schools. By 1993, there were nine such centres. Setting up its own technical workshops, however, has not proved cost-effective for World Vision, and it has dropped plans for further workshops. The third option is for trainees to be apprenticed to local artisans, who are given a small stipend by the organization as well as provided with some raw materials or extra tools. The programme covers a variety of skills from carpentry and bicycle repair to tailoring and weaving.

Typical of the trainees is a 14-year-old whose mother and father died of AIDS. He was left in the care of his grandparents, both in their 80s and both going blind. The boy had to do all the household chores before and after school, and inevitably he fell behind in class. When his teachers started calling him "stupid" he dropped out and went to ask the PCDW if he could go into skills training. Today, he is one of 10 trainees at a bicycle repair workshop whose owner has received, amongst other incentives, a bicycle from World Vision for his own transport.

At the end of their course, trainees are eligible for loans from World Vision to start up a business for themselves.

c) Income generation

The long-term sustainability of World Vision's orphan assistance programme depends on families' being able to pay their way and communities' supporting

their own institutions. Income generation is therefore one of the most important aspects of the programme.

The process usually starts with community mobilization—meetings at which ideas for income generation are discussed and associations are formed to start an enterprise. World Vision prefers to work with groups because training and other inputs have a wider impact, members offer mutual help and encouragement to each other, and a group is a more reliable unit for lending money. The organization offers training and advice from its technical specialists as well as access to equipment and loans.

A typical example of an income-generating project assisted by World Vision is that run by the Church of Uganda Women's Group. The group formed at the suggestion of the parish priest who had watched his congregation be decimated by AIDS. Some 70% of the women were widowed. The priest suggested they come together to support each other and care for the many children in their midst who had lost parents.

In 1992, nine women approached World Vision for help with starting an agricultural enterprise. They formed an association, got business advice and seed money from the organization and are now growing passion fruit and vegetables on a patch of land next to Kyotera Township Primary School. Until recently, the school was run by the church, and it was largely to secure the future of the institution and its children that the women started their business. Already the headmaster appeals to them for help with such things as food and soap at the school and extra support for the children he observes struggling.

In another example, a group of 30 men who came together to support each other through their economic and social problems, registered with World Vision as an association with a view to keeping bees. The members were caring for 26 orphans between them. World Vision gave training and a loan for 20 beehives and seven catcher boxes. In its first season, the association harvested nearly 25 litres of honey. However, the hives were subsequently plagued by lizards, bats and rats, and World Vision's bee expert was working with the men to try to solve the problem.

d) Agriculture

Besides the many small business enterprises that are farm-based, the agricultural programme is concerned with helping poor families improve the production of subsistence crops on their land so that they can feed themselves better. World Vision's agricultural trainer encourages farmers to form associations of 10–40 members to facilitate training and the extension of credit for inputs. A baseline agricultural survey established the most immediate needs. "We found that many families didn't possess the most basic tools, such as a hoe to work the land, and in some cases the four dollars it cost to buy one was beyond their means," reported the manager of the Rakai programme.

World Vision operates a revolving loan scheme for agricultural equipment and inputs such as seeds and chemicals. In 1993, 6,000 families caring for 12,000 orphaned children were benefiting from the programme, and World Vision says there have been noticeable results with extra land being put under cultivation.

e) Shelter

The baseline survey of Rakai observed that many people were living in houses in need of repair and that some were living in homes that were collapsing around them. World Vision therefore has a shelter programme aimed at rehabilitating homes or building new ones in partnership with families—though where orphaned children are living alone, the community is encouraged to help with labour and inputs. Potential beneficiaries are identified by the volunteer committees and the PCDWs.

f) Welfare

World Vision has recognized that the circumstances of some families in its project area are so dire that these families need extra help to survive. One example is the Senyonga family, in which 23 children between the ages of 5 and 15 years are being cared for by their grandmother, who is in her 70s. Josephine Senyonga brought up her seven children alone after the early death of her husband. She has watched five of them die of AIDS in recent years, leaving her their young children.

Another example is the Lubega family of four children, cared for by the eldest, 16-year-old Godfrey (see box). As beneficiaries of the welfare programme, the Lubegas and Senyongas get regular supplies of basic provisions and food. The 30 neediest families in every parish are eligible for welfare. They are identified by the parish volunteer committee, together with the PCDW, according to strict criteria. Those entitled to welfare are, for example, families of children living alone, families headed by a disabled or very elderly person and families with an unusually large number of dependents.

Coverage and costs

In World Vision's orphan assistance programme in Rakai many activities overlap and many people not directly involved also benefit. However, the following selected figures give a good idea of the scope of the programme. As of September 1993:

- the programme covered 330 villages in Rakai;
- 6,098 families caring for orphans were direct beneficiaries of World Vision activities, mainly education and agriculture (109 families were headed by orphans);
- 10,318 children were being supported in primary school, about 1,000 in pre-school, and 2,700 in secondary school or skills training;

Godfrey's story

In 1985 when he was eight years old, Godfrey Lubega's mother died of AIDS, leaving her four children in the care of their father, a brickmaker. In 1991, the children's father also succumbed to AIDS, and Godfrey, then 14, took over the care of his two younger brothers and his sister because there were no relatives nearby to take them in.

In a routine visit to the family, which had one child already supported in school by World Vision, the Parish Counsellor and Development Worker found Godfrey bedridden with advanced tuberculosis. The children's house was collapsing around them; there was no furniture inside, not even candles to light the place at night, and there was very little food. Outside, the small plot was choked with weeds, and a pig and a scrawny dog rooted about the yard. "The children and the animals were living in the same conditions," said Moses Dombo.

Taking stock of this desperate situation, the PCDW arranged for Godfrey to go to hospital, and she appealed to Mr. Lubega's former brick-making colleagues to help World Vision rebuild his house for the children. Today, Godfrey, partially paralysed though cured of his TB, looks after the home. With all that needs to be done on the smallholding, he has given up any idea of education for himself. Instead, all his hopes are invested in his brothers and sister, whom he is determined to get through school with the continued help of World Vision. "I'm their mother and father now," he said.

- about 1,000 children were benefiting from the welfare programme;
- 13 houses had been renovated or rebuilt under the shelter programme;
- five schools were in the course of rehabilitation—activities that benefit many more children than those whose education is supported by World Vision;
- over 6,000 families were benefiting directly from the agricultural programme;
- 224 groups and 50 individual families had started income-generating schemes. A further 180 applications had been received for help with developing small agricultural and business enterprises;
- 3,170 children were being helped through the sponsorship programme.

The initial three-year budget for Rakai was set at US$1,540,060, and the following selected figures give an idea of the costs involved in running the programme. In the 1992 financial year:

- $79,896 was spent on education;
- $32,201 was spent on construction (including schools, homes and health units);
- $98,158 was spent on administration and operating costs.

Problems faced by the programme

World Vision has experienced serious problems in the implementation of its orphan assistance programme. Most have been due to the bureaucratic requirements of its partnership with the Government and the World Bank, and the fact that funds promised have not been received in full. Underfunding and slow disbursement of government funds led to delays in the recruitment of staff at the beginning of the programme, and therefore in the registration of orphans.

Besides funding problems, World Vision has experienced inordinate delays in procuring materials and equipment for its programmes because of the requirement that all orders over a certain gross value must be put out to International Competitive Tendering to obtain the best price. This has applied to orders for bicycles for certain field staff, as well as to cement and corrugated iron roof sheets for the construction programme.

Two major agricultural projects—a grain-milling and a tractor-hire enterprise—were unable to start operations until long after teams had been trained, because of delays in gaining customs clearance for the machinery and registration for the tractors.

Getting through the red tape has taken up a good deal of staff time and energy. But while some of the implementing agencies of the poverty alleviation programme have been unable to operate at all, World Vision has been able to proceed more or less according to its original timetable by securing funds from its parent body in the United States.

The psychological needs of children

The manager of World Vision's Rakai programme tells the tale of a 12-year-old boy in Rakai who says he will never return to his family home just a mile away, where his brothers and sisters still live, because he cannot bear to see the grave of his much-loved father. He tells, too, of an 11-year-old and a 7-year-old who experienced the death of both parents from AIDS and then the death of their grandparents who had taken over their care. The two decided to walk to their mother's village 150 kilometres away to look for their relatives. They got as far as World Vision's office 30 kilometres away in Kyotera before they were stopped. "It was sheer desperation," he said. "They didn't know where or whom they were going to; they just felt there must be someone out there to call 'mother'."

The psychological state of such children is a matter of concern, but there is no clear understanding of the issue. People working with AIDS orphans in Uganda admit that this is an area of expertise that is particularly lacking in their programmes. "We have real difficulty getting kids to tell us how they feel," said Dombo. "But

there are many signs. When children sing, they sing of AIDS, and they sing and cry. In Luwero, they used to sing about war. In peaceful places, they sing of nature. But here they sing of 'Slim'."

In 1991, Redd Barna (Norwegian Save the Children Fund), which has a programme in Masaka District neighbouring Rakai, sent child psychologist Elizabeth Jareg to Uganda to assess the needs of children affected by AIDS. Her wide-ranging research revealed some common sources of psychological distress in the children. They included:

- witnessing the slow, miserable death of one, and possibly both, parents;
- often the subsequent loss of "their siblings, their home and property, their friends, school—in fact everything that until then has made up 'their world'";
- a move to an unfamiliar home and pattern of life, with little or no choice in the matter;
- schoolteachers unsympathetic to their difficulties and often too ready to punish them for being late or ill-equipped, without looking for explanations;
- experiencing relatives haggling over the division of their dead parents' property, sometimes immediately after the funeral;
- multiple loss, first of parents and then of the carers who had taken them in;
- the prospect for some of having to fend for themselves if their parents die;
- anxiety about abuse from adults, mostly relatives, and about having to drop out of school.

Dr. Jareg warns against assuming that children recover quickly from bereavement simply because they start to play and smile again. The death of a parent is the most profound loss a child can experience, and grief and depression often remain hidden—perhaps to surface later in disturbed behaviour.

NGOs' counselling services and other interventions on behalf of children, such as supporting them through school, go some way towards alleviating the distress and insecurity of orphans. And some programmes have activities aimed more specifically at dealing with psychological problems. Redd Barna, for example, teaches teachers and other adults the importance of listening to children and allowing opportunities for them to express themselves through a technique known as "Mediated Learning Experience".

Kitovu Hospital in Masaka, which has a home-care programme for people with AIDS and found itself drawn inevitably into working with affected children, runs group sessions for orphans once each school term. The sessions, attended by about 200 children at a time, take the whole day and are supervised by eight counsellors who engage children in play as well as discussion. The aim is to get the youngsters to open up, share their experiences and release stress. Kitovu also holds small group counselling sessions on school holidays, involving six or seven

children at a time in discussion, drama and songs designed to be fun as well as therapeutic.

But Sister Ursula Sharpe, who is behind the Kitovu home-care and orphan programmes, said: "I don't think we do a fraction of what needs to be done to help kids through their experiences of AIDS. Many kids are very resilient and do come through anyway. But many need something more."

Observations and lessons learned

While each society must find its own road in responding to the effects of the pandemic, Uganda's experience, in particular, offers lessons that can benefit other countries. Not only have Ugandans been dealing with these problems for several years, but they have been creative in developing responses and very ready to share their experiences.

One of the prime lessons to be learned is that open exchange of information and cooperation are essential. UCOBAC is a model for developing collaboration amongst NGOs, government ministries and donors, and for strengthening the capacity of small NGOs and community-based groups to care for children and to have access to funds. The Government, while very limited in its capacity to provide direct services for affected communities, has played a critically important role in policy leadership and creating an enabling environment for NGOs. Its readiness to admit the seriousness of its AIDS epidemic has been the key factor, and an example to other countries.

Because of the poor state of the economy, the Government of Uganda has depended heavily on donor support to enable it to carry out its responsibilities for children. UNICEF is helping the Ministry of Labour and Social Affairs to set up a countrywide system of orphan registers and data-processing facilities. At the district level in Rakai, Save the Children (UK)'s support for the Ministry's local staff has enabled them to play an important role in mobilizing community action for needy children, coordinating a multitude of NGOs, promoting compliance with the Government's policies concerning child care, ensuring that substandard orphanages have been shut down or improved, and protecting children's inheritance rights. Undoubtedly, the effectiveness of NGO programmes has been enhanced by the support and collaboration of committed government officers, and this is an example of creative funding by donors that could be adopted elsewhere.

Another lesson from Uganda is that relief and development should not be seen as mutually exclusive approaches to helping needy children. Many of the programmes visited recognize that the situation of some families is so dire that they are unable to take advantage of development or self-help initiatives until

their basic needs are met. This usually means food, fuel and possibly clothing, and some provision for relief supplies has been made in most programmes. However, as the magnitude of the problems caused by AIDS steadily increases—not only in Uganda but in other countries too—available donor support is stretched thinner and thinner. The priority for funds must, therefore, be long-term strategies that enable families and communities to support their children themselves.

Developing those strategies requires the active involvement of the families and communities concerned, as well as creative thinking and low-risk experimentation with innovative ideas. In Rakai, the use of animals for ploughing is an approach that deserves more attention, as does the possibility of setting up revolving loan schemes to enable families of children and elderly people to hire labour to make their land productive. Strategies that can free available labour from other tasks also have potential for helping families to increase their economic productivity. Cooperative day care as developed by *Basoka Kwavula* is a good example. The use of more fuel-efficient stoves and greater access to piped water could also free labour for other tasks. Another area needing urgent attention is the development of better marketing opportunities for families' excess produce.

In Rakai, there is a need to bring a broader range of technical skills to bear on the question of how to help families and communities increase their capacities for self-support. In particular, more attention needs to be paid to agricultural economics, micro- and macro-level economics generally, and business skills. For example, some doubt hangs over the future prospects of trainees in the vocational skills programmes, which appear to be based on the principle that vocational training is a good thing in itself, rather than on a clear analysis of the marketplace. There is a danger that the local economy, which is shrinking in the wake of AIDS, will not be able to absorb all those who come out of the training programmes.

There is general awareness among the organizations in Uganda assisting AIDS–affected children that the children's psychosocial needs deserve attention. This is another area where new expertise is required. Collaboration between the disciplines of psychology and social anthropology, for example, is needed to find culturally appropriate ways in which children can express their fears and grief at an early stage and thereby be helped to come to terms with them. This does not require new and separate programmes, but can be integrated into all services designed to meet the needs of affected children.

A related area also needing more attention is the stress experienced by staff of programmes working with AIDS–affected families. Dealing with sickness, death and their consequences on a daily basis is extremely stressful and can lead to "burn out". Staff need opportunities to express how they feel about what they are experiencing and opportunities for mutual support. World Vision's regular retreats are an example of an intelligent approach to this issue.

ZAMBIA

Background

Statistical profile	
Total population (1992)	8.6 million
Children under 16 years (1992)	4.4 million
Population growth rate (1980–1992)	3.4%
Population in absolute poverty (1980–1989)	
– rural	Data not available
– urban	25%
Population urbanized (1992)	42%
Average annual growth rate of urban population (1980–1992)	3.9%
GNP per capita (1991)	US$420
Average annual growth rate of GNP per capita (1980–1991)	-2.9%
Infant mortality rate (1992)	113/1,000
Daily per capita calorie supply as percentage of requirements (1988–1990)	87%
Primary school enrolment (gross) (1986–1991)	Boys—99%; girls—91%
Secondary school enrolment (gross) (1986–1991)	Boys—25%; girls—14%

The State of the World's Children 1994, UNICEF

Socio-economic and cultural context

Zambia's population growth has outstripped that of its economy. The number of jobs in the country's formal sector shrank by 2.4% during the 1980s, while the population grew at a rate of about 3.2% per year.[13] The weak economy has reduced the Government's capacity to fund such basic social services as health care and

education. Increasing economic pressure on families, intensified in the last two years by structural adjustment measures, has pushed some children out of the educational system and onto the street. The economic vulnerability of orphaned children increases the likelihood that they will have to leave school and find ways to generate income. They may have to leave their home as well, if housing was provided in connection with the father's employment or if it is claimed by the father's relatives.

Concern over HIV infection has contributed to "property grabbing" by members of a dead husband's family, leaving the widow and her children on their own without home or possessions. Most of Zambia's tribes are patrilineal, and when a man wishes to marry, he must pay a "bride price" to the family of the woman he is to marry. In urban areas, the practice continues, with the requisite number of cattle being calculated in cash. The payment to the bride's family establishes certain reciprocal obligations between the two extended families involved. The children of the marriage as well as their mother are seen as belonging to the father's family. In most tribes, it is traditional for a woman whose husband dies to be inherited by one of her dead husband's brothers and for her children to be considered as his. This practice has served the social welfare function of providing for the care of widows and orphans.

AIDS has contributed to changing this picture. Growing awareness of how the disease is transmitted has discouraged widow inheritance where it is likely that the husband died of AIDS. But if a widow cannot be inherited and the bride price has been paid, the husband's relatives may consider themselves entitled to take whatever property he had. Notwithstanding the likelihood that the husband infected the wife with HIV, his relatives may blame his death on her, reinforcing their sense of entitlement to his property. Zambian national law provides for the protection of widows and orphans, but it appears that in many situations, both urban and rural, traditional practices still hold sway.

The AIDS epidemic

In Zambia, the first AIDS cases were diagnosed in 1984.[14] The level of HIV infection is high in Zambia. Sentinel surveillance data from antenatal clinics collected in 1990 showed rates above 24% in most urban and peri-urban sites and from 13% and above in rural sites.[15] There is increasing openness about HIV/AIDS in Zambia which facilitates the work of organizations trying to assist affected children and families. A significant early factor in increasing awareness of the disease and its potential for infecting anyone was the public acknowledgement of former President Kenneth Kaunda in 1988 that his son had died of AIDS. President Frederick Chiluba, who came into office with the multiparty elections held in 1991, has continued to speak out about the threat of HIV and the need to prevent its spread. Despite such efforts, however, HIV/AIDS patients and their families still face stigmatization. The disease is dis-

A look at one neighbourhood

An enumeration and needs assessment survey carried out in 1991 by the Children in Distress Project of Family Health Trust (described below) provides some perspective on the situation of orphans in Lusaka. The study was carried out in Matero East, a low- to moderate-income community of about 3,200 residents where HIV prevalence is high. This study found that just over 10% of all children under age 21 in the area had lost one or both parents.

One of the coping strategies identified was that orphaned siblings are often divided among different members of the extended family. Younger children may go to live in a rural area, while school-age children stay in the city and try to continue their studies. The study found that well over half of the orphans identified in the community were separated from one or more of their siblings.

Almost 40% of the children who had a surviving parent were living with the parent, but about a third were living with another relative and about 15% were living in the care of an elder sibling. Among those who had lost both parents, most were living with a relative or with an adult sibling. Both institutional care and children living on their own were rare.

In Matero East, orphans were found to be disadvantaged in comparison to other children in connection with school attendance, but not as dramatically as might be anticipated. Among children 7–10 years of age, 68% of the orphans were in school compared to 75% of other children. For the 11–15 year age group, the figures were 79% and 88% and for those 16–20 years, 51% and 55%.

cussed openly, but many people are unwilling to talk about their own illness or that of a family member.

Child welfare services and policies

National policy on how best to address the needs of children affected by HIV/AIDS was in a formative stage in October 1993. Three months earlier, a national consultation on orphans had been held during which NGOs, relevant ministries, bilateral donors as well as UNICEF and WHO discussed the current situation and the action required. They recommended that the Government designate a lead ministry with responsibility for the welfare of children and called for establishment of a coordinating committee to oversee action to promote the welfare of children. A review of child legislation was called for and a task force established to develop a framework for coordination.

To help mitigate the difficulties families are facing in the wake of a range of economic structural adjustment measures, the Government is allocating funds as part of a "social safety net" programme. Some of these funds will be used specifically for the needs of orphaned children.

Children in distress: the CINDI organizations

In 1989, concerned professionals began a series of discussions on how best to respond to the needs of children affected by AIDS. They adopted CINDI (a contraction of "children in distress") as the name of their group. The Matero community in Lusaka (see box) was identified as the pilot area for research and action, and members of that community began to participate in the group's discussions. Late in 1990, several of those involved travelled to Uganda to learn more about what had been done there to define and respond to the needs of orphans.

Participants in the study visit brought back many ideas and a consensus that community-based programmes would be more appropriate than institutional care to the Zambian situation. But participants in the CINDI group began to move in different directions as they put their ideas into practice. In May 1991, a CINDI programme began to operate under the auspices of the Family Health Trust, a Zambian NGO responding to the impact of HIV/AIDS mainly in Lusaka and in Southern and Copperbelt Provinces. Others from the original group began to promote small community-based initiatives through the Society for Women and AIDS in Zambia (SWAAZ). A third group, known as *Kwasha Mukwenu*, whose leadership was involved in the initial CINDI discussions and the study visit to Uganda, started a community-based programme in the Matero community. Each of these is described below.

CINDI Family Health Trust

Family Health Trust is a Zambian NGO that was established in 1987 to respond to the AIDS epidemic in the country. Its main efforts include the Anti-AIDS Project, which provides AIDS education to children throughout the country; the Home-Based Care Project, which offers testing, counselling, clinical home care and AIDS education; and the Children in Distress Project (CINDI FHT), which provides care and support for orphans of age 20 and below.

The CINDI FHT staff includes a coordinator, two professional social workers based in Lusaka and a half-time social worker in the Copperbelt. The programme operates though nine independent, community-based groups, referred to as "branches" by CINDI FHT. Most have arisen from local concern about children in need, with members of the community asking CINDI FHT to help them organize a response. As a first step, each branch has agreed to enumerate orphans within their community and to make regular visits to those identified as being of particular concern.

Branch members are called "caretakers". Each agrees to make regular visits to certain children to provide emotional support and, as possible, material assistance. Most branches generate funds through membership dues and, in some

cases, income-generating projects. With the encouragement of CINDI FHT, some have been able to identify local organizations that can help meet children's needs.

The branches in Lusaka are able to request assistance from the CINDI FHT social workers when they identify children with material needs beyond the capacity of their own resources. Those in other provinces are essentially on their own to generate resources locally.

Most of the branches have between 8 and 20 members. The smallest has only 2, who are nurses at a health centre, and the largest, whose relationship to CINDI FHT is somewhat ambiguous, has 120 (see *Kwasha Mukwenu* below).

CINDI FHT has provided varying levels of support to its branches, depending on their particular needs and the availability of resources with which to respond. Two branches outside Lusaka have received bicycles and typewriters. Caretakers received training in a 1992 joint seminar, and five community workshops have also been organized.

The nine branches have identified just over 1,600 orphaned children with whom they maintain contact. About 1,300 of the children are in Lusaka. When a CINDI FHT social worker is notified by one of the Lusaka branches of specific needs in a family, she makes a home visit and does an assessment. If possible, this is done together with the caretaker for the children concerned. The social worker, based on her findings and the resources available, will assist them. Food, help with school expenses and clothing are the kinds of help most often provided.

About 200 children in the Lusaka area have received assistance from CINDI FHT to attend school, and a similar number have been given clothing. Fifteen families regularly receive food assistance. A few families have been given assistance with skills training or higher education. No particular efforts have yet been made to respond to children's psychosocial needs other than through the support provided by the caretakers through their periodic visits.

While there are other efforts to assist orphans in Lusaka, CINDI FHT is the largest, and it appears to be reaching only a fraction of the children in need. A conservative estimate of the number of orphaned children in Lusaka would be around 40,000, assuming about 8% of all minors have lost one or both parents (from any cause). While not all orphaned children would be expected to have acute needs, the majority are probably economically disadvantaged in comparison to other children.

Core budgetary support in 1993 for CINDI FHT of about US$50,000 came from the Norwegian Government's development agency, NORAD. Private donations of about US$6,000 have been used for direct assistance to children as well as food provided by the World Food Programme and clothing donated from Norway.

UNICEF has donated a computer and bicycles, funded the Matero East research and the 1992 training conference and paid for a study visit to Uganda. Recently, through the Government's social safety net initiative, CINDI FHT was allocated US$43,000 to assist families in need.

CINDI SWAAZ

The Society for Women and AIDS in Zambia (SWAAZ) is a membership organization that was inaugurated on 1 December 1989, the second World AIDS Day. Affiliated with the Society for Women and AIDS in Africa, it has a total of 120 members in its four branches. In addition to organizing workshops and other gatherings to raise awareness about HIV/AIDS and its effects on women and children, it has also worked with women in Lusaka's markets to help them develop prevention and control initiatives. SWAAZ has also started a hospital-based Family Support Project that provides testing, counselling and home-care assistance to families with an infected child.

SWAAZ's child-focused efforts have grown out of the concerns of 10 groups of market women they have helped to organize in the Lusaka area. SWAAZ has used focus group discussions to identify women's priorities, and children in distress have emerged as a major issue.

SWAAZ's main approach in helping groups respond to children's needs has been to provide seed money for income-generating initiatives that show the promise of being sustainable. Its most successful project of this type is at the Kaunda Square School. Using the equivalent of about US$400 provided by SWAAZ, the headmaster and a group of women started a "tuck shop" that sells snacks at the school. It has done well, and the proceeds have been used by those running the shop to provide varying levels of assistance to about 200 children in the school. To support such initiatives SWAAZ has raised funds locally and has received a small grant from the Ford Foundation as well.

In addition to its community-based efforts, SWAAZ has initiated a Family Support Programme for HIV–positive children and their parents. Based in the Department of Paediatrics of the University Teaching Hospital in Lusaka, it provides counselling and home-based care.

The Family Support Programme deals with the family as a unit. When the programme first began, if a child was suspected of being infected with HIV, he/she was tested and the mother informed of the result. Often the father, on learning his child was HIV–positive, would blame the mother and refuse to come in for testing himself. In at least one case, the husband abandoned the mother and child after learning of the child's infection.

A new approach is being used to help prevent such problems. Now when a child has clinical symptoms that suggest the possibility of HIV infection, the mother and father are called in together for counselling. Blood is drawn from the parents and child at the same time. The results are reported to the parents together, and additional counselling is done. In most cases, both parents are positive as well as the child. This has helped reduce blaming and tension between spouses and helped them to stay together to cope with the child's needs as well as the prospect of their own illness.

Families are offered the option of follow-up visits at home and support for home-based care as needed. Of the 169 families that have been seen initially at the hospital, 89 agreed to a follow-up visit and 25 have been visited at home on a regular basis.

One community's response: Kwasha Mukwenu

The *Kwasha Mukwenu* women's club, whose name means "assist your neighbour", operates in that spirit. It has 120 members from the community who volunteer their time, but has no paid staff. For group activities it uses space provided by the Matero Catholic Church. CINDI FHT did its initial assessment of orphaned children in this area and still provides food to some families there. Its social workers have, however, withdrawn from more active involvement in the community, since *Kwasha Mukwenu* is addressing needs there.

Kwasha Mukwenu members have identified some 420 children with diverse backgrounds who have lost one or both parents. Each member maintains contact with three or four families, visiting to provide emotional support and, as possible, material assistance. The secretary of the group is a teacher in the community. She saw the obstacles her students face with continuing their studies after a parent dies and decided to do something to help. She, like many of the members, tries to visit "her" children nearly every day and tries to be sensitive to cultural differences.

The group is trying to develop income-generating activities to help meet children's needs. UNICEF has provided five commercial sewing machines that the group plans to use to produce school uniforms for sale. The local Islamic Society has agreed to provide a refresher course in commercial sewing skills to 10 members of *Kwasha Mukwenu* as preparation for launching the initiative. Those trained will, in turn, train other members and children, as well as helping to produce uniforms. Needy students are to receive uniforms free. The national requirement that children must wear uniforms in order to attend school has been a barrier preventing some from continuing their education after a parent's income is lost.

Members of the group have already had some limited success helping children make and sell batik and tie-dyed cloth. They have approached the local member of parliament for assistance in securing land on which they want to do integrated farming. There would be a ready market for any food they could produce. Teaching boys carpentry skills is another practical initiative they hope to start soon. Tragically, carpentry skills are in demand to make coffins.

Observations and lessons learned

The programmes in Lusaka provide examples of approaches that, on a limited scale, have been useful in addressing needs among AIDS–affected children in urban areas. These initiatives need both additional support and constructive scrutiny from donors to try to develop models that can be used to address, on a much larger scale, problems emerging in the country.

A lesson that the CINDI FHT staff has learned is that unless the motivation to start a branch comes from the community, it is unlikely that there will be sufficient commitment from volunteers to sustain it and make it effective. In response to a request from an NGO working in Misisi, a particularly poor area on the edge of Lusaka, a branch was organized there. After some initial efforts the branch ceased to function. CINDI FHT staff found that most of the women who joined had done so more because they thought there might be something to gain from being part of the organization, than from concern about the needs of children in the community.

CINDI FHT has concentrated on addressing children's material needs. One way it might broaden its impact would be through early and more extensive collaboration with Family Health Trust's Home-Based Care team. Generally CINDI FHT's involvement with a family has not begun until a parent dies. The early involvement of a social worker or a branch member could help reduce the stress and trauma children experience with the illness and impending death of a parent.

The family counselling approach SWAAZ is using in their Family Support Programme deserves serious attention from organizations dealing with voluntary HIV testing and counselling.

Kwasha Mukwenu has learned a lesson particularly important for work in an urban context with a mix of ethnic groups. It is essential for members to respect the customs and beliefs of a child's ethnic group and not to try to impose their own traditions.

In 1993, Zambia had no overview of the numbers, needs or distribution within the country of AIDS–affected children. Zambian organizations addressing the needs of children orphaned by AIDS are working in an information and policy vacuum. Cooperation and coordination have been distressingly limited among

the NGOs involved in the area. The country urgently needs action-oriented research to provide a basis for building consensus, informed policies and coordinated efforts as well as mobilizing donor resources. A lesson learned in Uganda that seems pertinent to the situation in Zambia was that measuring the scale of the orphans problem proved vitally important in crystallizing the situation for policy makers, donors and child-oriented organizations, as well as to providing a basis for planning coordinated responses.

Zambia and Uganda: similarities and differences

The patterns and effects of the HIV/AIDS epidemic in Zambia have some similarities with those in Uganda as well as some significant differences. HIV prevalence rates are high and at similar levels in the two countries, higher in cities and towns but significant in rural areas as well. Tragically, each has large numbers of children whose parents are HIV-infected, sick or have died of AIDS. Falling commodity prices and policies of former governments have generated economic difficulties in both countries, and both are struggling with the hardships of structural readjustment.

Even with these similarities, the problems of AIDS-affected children are manifesting themselves differently in the two countries. Zambia has almost as many urban residents as it does rural, a significant contrast to Uganda where the population is overwhelmingly rural. Also, an apparent social consequence of Zambia's urbanization has been a weakening of the links of Zambian city dwellers to their extended family members in rural areas. As a result of these two factors, the problems of HIV/AIDS-affected children are much more apparent in Lusaka than in Kampala, cities of similar size and similar levels of HIV infection.

This difference has very significant programmatic consequences. Zambia faces substantial problems among HIV/AIDS-affected children on two fronts, urban and rural, while the problems in Uganda at the current stage of the epidemic are predominantly rural. A fundamental issue most AIDS-affected families face in rural areas is how to maintain agricultural production. The resource of land remains despite morbidity and mortality; the question is how to make it productive. In cities, however, the essential resource of a family is the capacity of its members to generate income, which is directly reduced due to AIDS. The strategies for intervention, particularly efforts to support sustainable coping strategies among families, have to be very different between cities and rural villages.

KENYA

Background

Statistical profile	
Total population (1992)	25.2 million
Children under 16 years (1992)	12.8 million
Population growth rate (1980–1992)	3.5%
Population in absolute poverty (1980–1989)	
– rural	55%
– urban	10%
Population urbanized (1992)	25%
Average annual growth rate of urban population (1980–1992)	7.3%
GNP per capita (1991)	US$340
Average annual growth rate of GNP per capita (1980–1991)	0.3%
Infant mortality rate (1992)	51/1,000
Daily per capita calorie supply as percentage of requirements (1988–1990)	89%
Primary school enrolment (gross) (1986–1991)	Boys—96%; girls—92%
Secondary school enrolment (gross) (1986–1991)	Boys—27%; girls—19%

The State of the World's Children 1994, UNICEF

Socio-economic and cultural context

Kenya has been especially successful in attracting foreign investment; yet its economic growth remains disappointing, and the distribution of wealth is very unequal. About 80% of its citizens live on the 17% of the land that is arable. The population growth rate has been one of the highest in the world and has led to

increasing pressure on the land, which, coupled with the attraction of economic activity in cities, has led to heavy urban migration.[16]

Over 40% of Nairobi's 2 million–plus inhabitants live a precarious existence in slum and squatter settlements in and around the city, facing the constant threat of eviction. The majority of families are headed by women struggling to survive through casual labour or petty trading. In many of these families, children contribute income through collecting and recycling paper or plastic, scavenging in the garbage dump and various other activities. An estimated 130,000 children work on the street, some 25,000 of whom live there full time. Few children in the slums have access to schools.

The health risks children face in the slums are enormous. They lack ready access to piped water. Most are malnourished. Housing is crowded, smoky and often makeshift. Dysentery, food poisoning and respiratory infections are common among children. Abuse and violence frequently are facts of life.

Children living on the street are even more vulnerable than those with families in the slums. Many have fled intolerable relationships in impoverished, broken or abusive homes. Recently AIDS has become another factor pushing children onto the streets, as parents die and relatives are unable or unwilling to provide care. Some street children are involved in sniffing glue or solvents, and their level of sexual activity is high, bringing the risk of sexually transmitted diseases, including AIDS.

The AIDS epidemic

HIV infection rates are significantly higher in urban areas than in rural ones. In 1992, HIV prevalence rates overall were around 10% at urban sentinel surveillance sites, but in the 20–30% range at some antenatal clinics. This compared to 4.5% at rural sites.[17] The National AIDS Control Programme has estimated that up to one million Kenyans are HIV–positive, about 3% of whom are children below three years of age. The number of AIDS cases is doubling every six to nine months, and by 1996 it is expected that some 300,000 children under age 15 will have lost a parent to AIDS.[16]

Efforts to promote effective responses to the needs of children affected by AIDS have been hampered by the intense negative reactions associated with the disease. AIDS is strongly feared in Kenya, and those with the disease are often stigmatized and rejected, even by their own families.

Child welfare services and policies

The Department of Children's Services of the Ministry of Home Affairs has a mandate for formulating and coordinating national policy for children. They have

a limited number of children's officers at the district level who try to arrange care and services for children who have been orphaned, abandoned, sexually abused or otherwise left in difficult circumstances. The AIDS epidemic, however, has presented new problems.

Return to a rural area

The solution often favoured by those in cities trying to help orphaned children find a better future, if not simply an improved chance of survival, is to help them return to members of their extended family in a rural area. As the experience of one group of brothers suggests, such a journey may be only the beginning point for a child's struggle to survive.

"John" grew up with his three brothers in the port city of Mombasa. His father was a mason and casual labourer who earned enough to send all of the boys to school. When their father fell ill, however, the family's limited resources were used for his treatment. As the money ran out, return to the father's family home in Nyanza Province seemed the only option left for the family. Unable to borrow from friends the money for the journey across Kenya, John's father finally wrote asking his father to send money for their fare. John's grandfather sold some of what little land he had to bring his son and his family home.

John's father died in 1991 not long after he and his wife and the three boys arrived in the small village some 30 miles south of Kisumu. John's mother died the following year. His grandfather no longer had the strength to work the small plot of land he still owned. John's step-grandmother was the only one in the family physically able to do such work. What little cash income the family had came from the occasional jobs she was able to do for neighbours, typically earning 10 shillings (about 15 US cents) a day. The rains were erratic during the last growing season, and the grandfather's land, like that of others in the area, produced almost nothing.

The four boys attended school off and on when they first arrived in the village, but John, at age 13, and his brothers finally had to drop out. This was not only because there was no money for fees and other expenses, but also because their help was needed with finding ways for the family to survive. Some days the brothers were able to catch a few fish. After the rice harvest, the boys were able to collect a little grain that had fallen on the ground around the local mill. Part of this they ate raw, bringing the rest home to share. Asked what they did when there was no food, the grandfather said simply that they slept.

Had they stayed in Mombasa, the street would have offered the most likely avenue for the boys' survival. In their part of rural Nyanza, there are no programmes designed to help children like John. There are, however, NGOs that have started to meet monthly in Kisumu to explore how best to meet the needs of vulnerable children. The Department of Children's Services has visited the family. Perhaps they will be able to find an organization that can help them find a way to survive.

The one time John smiled during the visit to his family was when he was asked to pose for a picture with the doves he is raising. For a moment there was a trace of pride in his face as he stood beside the coop he had built and held one of his birds.

About 10 abandoned children each week come to the attention of the Department. Most are left in hospitals by adolescent mothers. About half of these infants test positive for HIV antibodies. While other abandoned infants are routinely placed in foster care, those with positive HIV tests are only placed in institutions. The Department has been unable to find foster or adoptive families willing to take them. These infants remain in institutional care until it can be determined whether they actually have the virus, usually at around 18 months of age. Until 1990, there were no homes that would accept HIV–positive infants. Now, there is Nyumbani and one or two others that will reluctantly take them in.

The Department has established a National Children's Committee to address policy issues. It is also developing a network of district-level Children's Committees. Members include the district-level children's services officers, NGOs, churches and other local groups. They play a role in allocating government funds for use within a district. They are also establishing Children's Committees at the division level. Recognizing the limited capacity of the Government to provide services for vulnerable children, the intention is that these groups will monitor the situation of children at the village or community level, identify children in need of help and try to mobilize local resources.

The Undugu Society

"Undugu" is a Kiswahili word meaning "brotherhood" or "sisterhood". The Society was founded in 1973 by a Dutch missionary who had been posted to a poor and densely populated parish in Nairobi. He acquired a modest building in the city and opened it as a drop-in centre for street children where they could be assured of a meal, shelter from bad weather and a refuge from police harassment.

Over the 20 years of its existence, the Undugu Society's activities have evolved from the "curative" approach of social welfare towards a more preventive approach in which Undugu staff—all Kenyan nationals—work in partnership with the poor urban communities from which street children come, helping them to improve their social and economic conditions.

The Society reckons that in Nairobi alone there are around 130,000 children working, and sometimes living entirely, on the streets. Many have fled intolerable relationships in broken or abusive homes. Recently, AIDS has become another important factor pushing children onto the streets, as parents have died and relatives have been unable or unwilling to care for those left behind. Undugu makes no attempt to single out such children; its guiding principle is that all street children be treated equally, regardless of the circumstances that made them homeless.

However, recognizing that AIDS does pose new and unique challenges to the communities with which Undugu works—and that street children are especially

vulnerable to HIV infection—the Society has recently drawn up a plan to integrate AIDS education and control measures into all its activities. The plan also contains suggestions that efforts be made by Undugu to reach out to families affected by AIDS so that timely provision can be made for the care of the children.

Organizational structure

Undugu has a 10-member Board of Directors, which reports to a council made up of board members and the Society's trustees. An executive director is responsible for the day-to-day running of the organization, which has four departments:

a) community development;
b) informal training and business development;
c) low-cost housing; and
d) administrative support.

The Society employs a staff of around 150 people, including 20 social workers, 5 professional skills trainers, a community nurse, 14 teachers and 20 administrative staff.

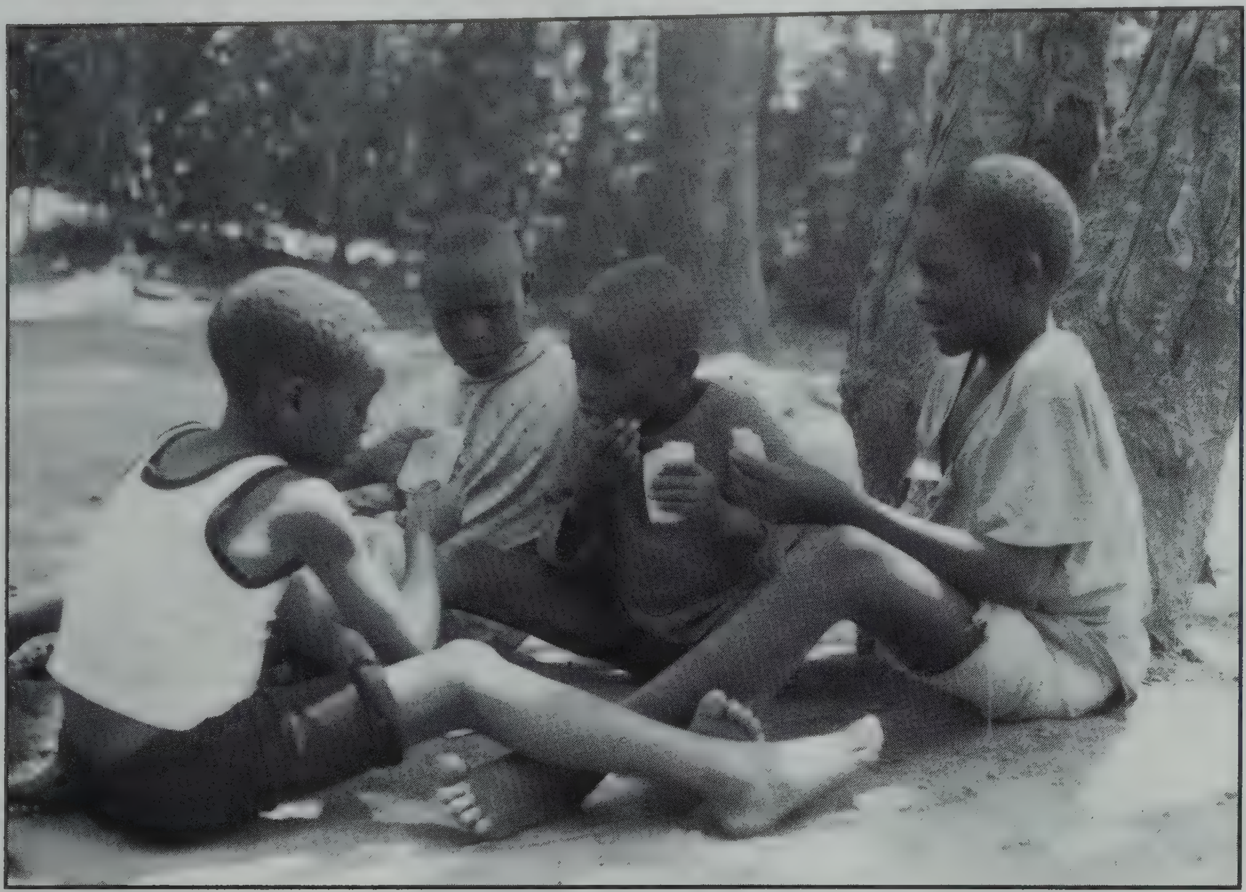
The "parking boys" programme

A popular way for Nairobi's destitute children to earn a few coins is to guide drivers into empty spaces in the busy town centre—hence, they are commonly known as "parking boys".

The Undugu Society still runs a drop-in, or "rescue", centre where such children—many of whom also survive by scavenging alongside vultures and huge maribou storks in the municipal garbage dumps—can shower and wash their clothes. The centre offers food, shelter, health care and, if need be, counselling.

The guiding principle at Undugu homes is to allow children to leave the streets at their own pace without pressure from anyone. Thus, they are free to come and go from the home at will. When they first arrive, street kids tend to be unwilling to trust anyone. But gradually, as they gain confidence, they begin to talk to the house mother, or to volunteers who work at the home and who are often ex–street kids themselves. Only then can rehabilitation begin, and in rare cases children have come and gone from the home for several years before expressing the wish to leave the streets for good.

Many value their independence deeply, and they find it particularly difficult to adjust to having no money of their own. Said one house mother, "It is a rule that we never hand out money. If we want to pay for a meal for someone, we give the money directly to the shopkeeper or cafe, and the youngster can go for the food."



There are several alternative paths for leaving street life that Undugu explores with its clients. Sometimes a youngster who has walked out of a bad home situation can, with the help of social workers, be reconciled with his family and return home, with continuing support from the social worker if necessary. If a youngster's family is far from Nairobi and he wants to go home, Undugu may contact another NGO working in his home area to take over responsibility for helping the family.

Millions of children orphaned by AIDS drop out of school and join those millions already on the street.

Whether a child returns home or not, Undugu believes education is the key to long-term rehabilitation. If possible, the Society helps a child return to the mainstream by attending his local government school, working out with the family on a case-by-case basis the level of assistance Undugu will give. (There are no tuition fees for primary school, but parents are still faced with costs for uniforms, books and materials, building levies, etc.)

For many of Undugu's clients, however, going to mainstream schools is not an option. They have missed too much time to be able to catch up. Besides, head teachers are often reluctant to take in what they consider problem pupils whose behaviour may be disruptive. For these youngsters, Undugu runs its own schools, which fall into two categories. There are the "Machuma schools" ("chuma" means metal in Kiswahili) set up originally to cater for the needs of youngsters who survive by collecting and selling scrap metal. They cater for around 240 children and are part time, thus giving the children the chance for a basic education while allowing them time also to pursue the occupation that sustains them.

Then there is Undugu's Basic Education Programme (UBEP), which runs four schools catering for around 600 slum children at a time. UBEP schools teach basic literacy and numeracy according to a special three-year syllabus approved by the Kenyan Government. No uniform is required, and youngsters of all ages learn together, grouped according to ability. Always anxious to discourage dependency, Undugu does not provide a school meal, and everyday problems of poverty continue to dog the pupils. The drop-out rate is high: only around 25% of entrants complete the course.

For those who do complete the course, there is the opportunity to learn a skill in the fourth year through an informal training programme. Youngsters are attached to artisans in the informal sector and can choose from a wide variety of occupations, from hairdressing and knitting, to shoemaking, watch repair and carpentry.

The idea of placing trainees in existing workshops is to ensure that the skills they learn are relevant to the community and that they gain firsthand experience of working life. The training is supplemented by Saturday morning theory classes organized by Undugu, where trainees are taught basic business skills that will help them eventually run their own enterprises. In September 1993, about 120 youngsters were benefiting from this programme.

Those with the most ambition, and who have demonstrated their commitment to leaving the streets, get the opportunity to upgrade their skills in Undugu's Production Unit, which has workshops and training programmes for carpentry, motor mechanics and metalwork run by professional craftsmen.

Until 1992, Undugu's workshops were supported by funds from the Society. But recognizing that its dependency on outside donors made the scheme vulnerable, the Society decided the workshops should try to support themselves through selling their products. A Design Unit was established to improve the quality and design of all products to ensure their marketability and, with dynamic leadership, the Production Units were already making a small profit by 1993.

Initial problems with the commercialization process were ironed out through intensive group discussion, and a profit-sharing scheme instituted as an incentive. A measure of the success of the workshops is that, from time to time, employers come looking for skilled workers to employ. But Undugu also has a Business Development Unit, which tries to place qualified youngsters from its training schemes in jobs or to help them set up in business for themselves with advice and credit. The unit also offers consultancy services to the informal business sector.

The street girls programme

In Undugu's experience, the rehabilitation of female street children is especially challenging. Most street girls prostitute themselves at some time or another to survive. Besides, street girls are often forced into more or less formalized sexual relationships with older street boys to secure their protection and the right to "belong" to a particular gang. The stigma of this life clings even after rehabilitation, making it difficult for the girls to find marriage partners and status within the community.

Believing that young girls find it harder to take an independent stand because of the influence of their boyfriends, Undugu felt it necessary to establish a home for the girls well away from their normal environment. The Society has rented an old house on a coffee estate about 35 kilometres from Nairobi. Most of the teenagers go to boarding schools, while younger girls attend local schools. Others who are part of the programme may be back living at home or in rented accommodations in town while taking vocational training courses.

In late 1993, the house among the coffee fields had 36 residents ranging in age from 6 to 17 years and looked after by one house mother with the help of one or two volunteers. In this programme, the principle of allowing street children to set their own pace for rehabilitation has been somewhat sacrificed in the more immediate interests of the girls' safety. The house is too far from town to allow the girls to come and go at will. Homesickness and confusion of purpose are fairly common, and in 1993, 10 youngsters dropped out within a six-month period.

All girls entering the programme are given thorough health checks. Sexually transmitted diseases are common, and recently, high levels of HIV infection have been found among them. Of a group of 22 girls, 7 tested HIV–positive, and the rate was 20% in another group of 60 girls, underlining the intense vulnerability of young girls on the streets: they are increasingly sought out as sex partners by men who believe that very young girls are less likely to infect them than older prostitutes. Their HIV test results are communicated only to the girls themselves, Undugu's health staff and the house mother. No discrimination was observed in the home.

Funding

Undugu receives funds from a large number of sources, predominantly large development agencies based in Europe and North America. It has built up trusting relationships with its donors, who tend to be regular and reliable supporters.

In July 1993, the Society instituted a scheme aimed at raising some funds from the general public locally, but, equally importantly, at raising awareness of the issue of street children. Under the scheme, people are encouraged to buy from the Society books containing ten coupons each worth 10 shillings (approximately 14 US cents), which are designed to be handed out instead of coins to children begging in the street. The coupon ostensibly entitles the child to a shower and a meal at the drop-in centre. These amenities are in fact freely available to street children, but the coupon is expected to act as an incentive to them, while at the same time reminding the giver of Undugu and its services.

Undugu's total budget for 1992 was around US$830,000. Since the general election in December of that year, inflation has increased dramatically, seriously undermining the Society's efforts to provide services and to establish youngsters in their own small business enterprises.

Nyumbani Children's Home

Nyumbani is a bright, single-storey building set in a spacious plot on the outskirts of Nairobi. There is a well-equipped playground outside and spacious nurseries inside. The atmosphere is one of cleanliness, kindness and efficiency.

Nyumbani (meaning "home" in Kiswahili) was opened in September 1992 by an American physician and psychiatrist working in Kenya who had observed serious discrimination in children's homes and hospitals against babies believed to be HIV–infected—and even sometimes against those whose parents had died of AIDS. Such babies were almost invariably dirty, unfed and unloved. Some were actually dying of neglect because of the fear of staff members, and the doctor realized there was an urgent need for a place where infected youngsters could be cared for properly.

The home can accommodate 40 children at a time, and to date 46 have passed through its doors. In September 1993, there were 24 residents between the ages of five weeks and six years. Running costs are around US$7,200 per month, with drugs being the most expensive items on the budget. Funding is very uncertain: Nyumbani relies entirely on private donations, getting no support from the Child Welfare Society or from the Kenyan Government, though it has recently been officially recognized as a hospice for children with HIV/AIDS.

Children come from many different orphanages and hospitals, but some are brought to the home by relatives after mothers and/or fathers have died of AIDS, because the relatives are afraid to keep them. Nyumbani is not intended to be a long-stay institution, but a refuge for babies in crisis. The objective is to return every child to the community. Those who prove not to be HIV–infected after 18–24 months—the period it takes for the mother's antibodies to clear from her baby's bloodstream—are referred to the Child Welfare Society, which will either trace the relatives and return the child to them or offer the child for adoption or fostering.

However, the process of returning those babies who prove to be HIV–infected to their families is usually very slow and often impossible. Nyumbani encourages the family to visit, and tries gradually to dispel the fear and prejudice that prevent them from giving the child a home. Relatives come with mixed feelings, said the matron. Sometimes there has been division in the family about whether to give the

little one a home, and the task then is to win over the doubters. Sometimes families have been unable to bear the prejudice of neighbours and the threat of being ostracized if they take in the child of a relative who has died of AIDS.

The home is served by a Board of Directors, but day-to-day administration is in the hands of the founder and two professional nurses. Fifteen "mothers" work in shifts, with three or four on duty at a time. They are helped occasionally by volunteers. Two doctors serve the home, visiting regularly and being on call for emergencies.

Every weekday, two sisters from the local Catholic community come to Nyumbani to offer lessons. Classes for the infants are informal, with drawing, reading, singing and games for whoever wants to join in. For the 4- to 6-year-olds, there are more structured lessons. So far, schools in the neighbourhood have refused to take in any of Nyumbani's children, causing serious depression in some who are old enough to remember a more normal family life.

To educate the general public and try to dispel fear and prejudice, Nyumbani has video shows, talks and discussions. The staff also encourage visits to the home, during which people ask all kinds of questions about how the staff protect themselves, and what they do when, for example, a child has diarrhoea or vomits. "Changing attitudes takes a lot of patient explaining," said the matron.

"An institution like Nyumbani is not the best place for a child," she added. "Children need to be brought up in the community and to belong. Here they belong to no one. But at the moment, Nyumbani is necessary because of the stigma of AIDS and the neglect of affected children."

Observations and lessons learned

Stigmatization and discrimination against people with HIV/AIDS and their children are serious and widespread in Kenya. This sad situation, which causes great personal pain and hampers efforts to respond to the needs of affected children, may in part be due to the reluctance of the Government to admit to the seriousness and significance of the epidemic. Since June 1993, senior government officials have begun to address publicly the importance of preventing the spread of HIV. This move towards greater openness should be encouraged.

There is still a good deal of confusion about the transmission of HIV and the nature of AIDS. This has caused particular problems for Nyumbani. The fact that a child carries maternal antibodies in its bloodstream for the early months of its life, and that the child's own sero-status cannot easily be established until these clear, is a difficult concept. When babies brought to Nyumbani prove eventually to be clear of HIV, the media have sometimes credited the home with miracles.

Nyumbani is one of very few programmes in Kenya set up specifically to address the needs of AIDS–affected children, and its efforts to reach out to families and the general public to teach by example are filling an important gap.

The Undugu Society, established to help street children, is inevitably finding itself confronting the challenge of AIDS, as the epidemic has become another factor forcing children into poverty and sometimes onto the streets to survive. Several aspects of its programme deserve highlighting:

- Allowing street children to set their own pace for rehabilitation and not burdening them with expectations appears to be an effective way to build trust and minimize the drop-out rate from rehabilitation.
- Undugu has an outreach bus in which staff go every Monday night to visit the *chooms*—the alleyways where street children gather to sleep at night. These regular visits keep Undugu's staff in touch with the reality of the children's lives and help them design rehabilitation programmes that are truly responsive to the children's needs. They also build up the children's trust in Undugu.
- The staff at Undugu homes and reception centres believe it is important to set an example for the children, and they make it a rule never to smoke cigarettes or drink alcohol on the premises.
- The Machuma schools recognize the fact that if school hours are in conflict with the children's work patterns and therefore a threat to their survival, they will simply not attend school. So the hours are set to accommodate the children's other activities.
- Because it is based on sound analysis of the marketplace rather than on a belief that skills training is intrinsically valuable, Undugu's training scheme had little difficulty in becoming self-financing. This approach also ensures that youngsters are not given skills for which there is no demand.
- Recognizing the vulnerable egos of children used to being rejected and despised, as well as the lack of respect many street children have for authority, discipline in Undugu's homes is maintained as far as possible by peer pressure, which is encouraged by bringing everyone in the home together to discuss problem behaviour.

RWANDA*

Background

Statistical profile	
Total population (1992)	7.5 million
Children under 16 years (1992)	3.9 million
Population growth rate (1980–1992)	3.1%
Population in absolute poverty (1980–1989)	
- rural	90%
- urban	30%
Population urbanized (1992)	6%
Average annual growth rate of urban population (1980–1992)	4.8%
GNP per capita (1991)	US$270
Average annual growth rate of GNP per capita (1980–1991)	-2.4%
Infant mortality	131/1,000
Daily per capita calorie supply as percentage of requirements (1988–1990)	82%
Primary school enrolment (gross) (1986–1991)	Boys—69%; girls—68%
Secondary school enrolment (gross) (1986–1991)	Boys—9%; girls—6%

The State of the World's Children 1994, UNICEF

Socio-economic and cultural context

With the highest population density in Africa and a population that is 95% rural, Rwanda is one of the least-developed countries in the world. The economic

*The information presented in this section was collected in September 1993. At the time of the writing no information was available to update this section in the wake of the recent tragic events in Rwanda.

situation has declined progressively since 1987 and precipitously after the collapse of world coffee prices in 1989 and the onset of war in 1990. In 1989, Rwanda also had the highest fertility rate in the world. Most families are experiencing intense economic pressure. There is fierce competition to survive in both rural and urban areas, weakening traditions of mutual support even within families.[18]

Several factors contribute to a situation in Rwanda that presents particular difficulties for children whose families are affected by HIV/AIDS. As in the rest of sub-Saharan Africa, for most people the extended family is the social-welfare safety net. Without it, those who are poor, and particularly children, are extremely vulnerable. Poverty, the breakdown of traditions supporting formal marriage, and the epidemic have the combined effect of leaving many children with no extended family to provide for their care.

The marital status of children's parents in Rwanda has a significant bearing on their situation if they are orphaned. If the parents have been married (which involves both the payment of a traditional bride price by the prospective groom and completion of the necessary legal papers), then orphaned children are considered as belonging to the father's family and, in most cases, will be taken in by someone within his family. Decisions as to who will care for children when both parents have died are made by the eldest male member of the family, usually the grandfather or oldest uncle.

Children whose parents were not formally married are in a less clear situation. With urbanization and modernization has come a weakening of traditions. Cohabitation without marriage is common, particularly where poverty makes the payment of a bride price impossible. Where parents are not legally married, the father's family may reject the children and their mother and take the father's home and property. If the mother and/or the children are rejected by the father's family, there is no assurance that they will be accepted by the mother's family either. This means, effectively, that there are some orphaned children who do not have an extended family, a situation that seems to be fairly common in urban areas.

The AIDS epidemic

AIDS in Rwanda has been primarily an urban phenomenon. In 1991, rates of HIV infection among adults in Kigali were found to be in the 27–30% range, only slightly higher than in 1986. Rural rates of infection were low in 1986, generally between 0 and 2%, and in 1991, were found to remain in the 2–3% range. Infection rates in semi-urban (towns and peri-urban) areas, however, increased markedly in the same period to about 8%.

Since HIV infection has been most prevalent in the urban areas in Rwanda, it is in these areas that the largest numbers of children orphaned by the epidemic are found. Poverty together with the social and cultural changes that have discour-

aged marriage for many couples leave many such orphaned children destitute and without recognition by an extended family.

Child welfare services and policy

In 1993, a network of government and NGO services in Kigali were responding to the needs of individuals and families affected by AIDS. There were eight Social Assistance Bureaux located in various parts of Kigali, staffed by trained personnel employed by the Ministry of Social Affairs. The Catholic NGO Caritas Rwanda channelled food assistance (using commodities provided by the World Food Programme) and medicines for the treatment of opportunistic infections of people with AIDS through these centres. Caritas also provided funds that enabled the government social workers to support income-generating activities among adults who were sick but able to work and to pay rent for widowed or single mothers and funeral expenses for needy families.

Where possible, the social workers placed orphaned children with members of their extended families. Where this was not possible, they placed orphaned children in "family homes" established by Caritas Rwanda.

The privately supported Bilyogo Medical and Social Centre provided counselling, HIV testing and medical treatment, and collaborated with the Caritas-supported social workers in the placement of orphaned children. The Swiss NGO Terre des Hommes, Lausanne, with the active involvement of neighbourhood people, operated two canteens. Each provided one meal a day six days a week for children who were orphaned, extremely poor and/or on the street.

The family homes of Caritas Rwanda

Since the AIDS epidemic began to unfold in the country, the social assistants of the Ministry of Social Affairs and Caritas Rwanda have collaborated in supporting and finding placements for children whose parents could no longer provide care. The first step is to look for a family member who can do so. In some cases, this has proved possible, but, for the reasons already presented, in a significant number of cases no one could be identified who was willing and able to provide care for orphaned children. They began to see the need for another type of care.

Initially, they considered building an orphanage. They rejected this option, however, recognizing that children who grew up in such a setting would not receive the personal love and attention they would from a "mother". They also knew an orphanage would be fairly conspicuous wherever it was built, and that a large group of children orphaned by AIDS might be stigmatized. Protecting them from community contact by incorporating a school into the orphanage would be

both expensive and would cut them off from the world into which they would eventually have to integrate. This line of reasoning led Caritas to decide to establish *maisons familiales*, "family homes", that would, so far as possible, replicate normal family life in the community for orphaned children who could not be cared for by relatives.

With the objective of giving love and care to orphaned children in a family environment, Caritas recognized that finding suitable "mothers" was crucial to the success of the family home idea. The social assistants identified mature women who were widowed or abandoned, had no more than two children of their own and were themselves in financial need. Those selected and placed in a family home receive a monthly stipend from Caritas, but their role is clearly defined as that of a mother, not just a paid care provider.

Where a social assistant from one of the eight bureaux is unable to find relatives or a family friend willing to provide care, she discusses the family home option with the sick parent and later with the children. If they agree, the children stay with the natural parent until she or he dies, then they are moved to the family home.

Caritas decided to purchase rather than rent houses and to establish the homes in various parts of the city. The organization felt renting might not ensure the stability the children needed, since a landlord could take the property back at any time, forcing the children to move and experience yet another displacement. In keeping with the guiding principle of replicating normal family life in the community, the houses purchased have been of the same standard as others in the same area and furnishings have been adequate but basic. The houses are in different parts of the city to avoid creation of an orphans' "ghetto".

In principle, each family home is to have 10 people, including the mother, her natural children and the children placed with her. Siblings are placed together, so the number of children in a given home varies.

The children and the mothers are encouraged to become a genuine family unit. The observations of the social assistants managing the programme and the visit to a family home established only two months before suggested that such a process was well under way. In the home visited, 3 groups of orphaned siblings together with the mother's own 2 children made a total of 11 children (4 girls and 7 boys from 5 to 12 years of age). Initially, each of the sibling groups had stayed away from the others, but this lasted only a short time. When asked about the children's emotional adjustment to their new situation, the mother replied that each had individually told to her, at one time or another, his or her own story about the loss of the natural parents. Having done so, the child would begin to respond to her as the mother.

The social assistant who monitors and supports the family homes said that almost all of the children who had been placed in them had adjusted well. She

observed how different the behaviour of the children was following the loss of their surviving parent, when they were extremely sad and withdrawn. She noted, however, that the adjustment to the family home and acceptance of the mother had been easier for younger children than for those over 12 years of age.

A family home was visited and it was clear from the questions asked by the mother that she would benefit from training about how HIV infection is and is not transmitted and what measures (such as protecting any open wounds from contact with blood or other body fluids from a sick child) she or the other children could take to reduce what small risk of infection there might be. The coordinator of the programme said training on this and other subjects, such as the children's psychosocial needs, was planned.

Children are expected to go to school and to work in the home as they would in a typical Rwandan family. Family life at another level is also being replicated spontaneously. The mothers, who also meet as a group with the social assistant each week, have been visiting each other's homes, sometimes together with the children.

The first family home was established at the end of 1991. A total of seven homes had been established by September 1993, six of them in Kigali. Two more were due to open within a month. The war had cut off from Caritas support the one home established in Ruhengeri in northern Rwanda. The children in the home had reportedly dispersed. Caritas planned to reopen the home as soon as they could gain access to the area. A Catholic sister in the town of Gisenyi was also reported to be preparing to open a family home with Caritas support.

No policy has been established regarding how long children living in family homes will be assisted. In principle, it will be until they have attained sufficient education or training to become self-supporting.

In September 1993, a total of 52 children were living in six family homes. The whereabouts of the eight children who had been in the Ruhengeri home was not known. It was not possible to assess the extent to which orphaned children in Kigali, a city of about 250,000 people, have fallen through the extended family and social assistance safety nets and remain without care. With the network of social assistance bureaux and NGO programmes, the impression was that there were not large numbers of such children.

Only in one case had it been necessary to replace a mother. In that instance, it became clear within a very short time that a mistake had been made in selection, and she was replaced.

An average of two children per family home have been ill periodically, possibly as a result of AIDS, but they have not been tested for HIV. One child has died since the programme was established. The care of those who are ill has been a

major time demand and concern of the mothers. Caritas plans to open two special homes for the care of sick children needing a level of care beyond what can be provided by the family home mothers. Once recovered, children are to return to their own family homes.

The purchase price of the homes has been in the range of US$3,448–4,138. Additional funds have been required for repairs in some cases.

Each of the mothers is provided US$0.65 per child living in the home per day plus US$12.90 per month for herself, making a total annual cost per orphan of about US$270. Additional annual costs not included in this figure include school fees for all children of US$6,166 and the salary of US$179 per year (which is paid by the Ministry of Social Affairs and supplemented by Caritas) of the social assistant who monitors and supports the homes. Combining all these items, the annual cost per child is approximately US$392. This does not include the administrative costs of Caritas Rwanda.

The homes have been established with the recognition, as with a traditional orphanage, that their continuation depends on ongoing financial support, which for the foreseeable future will have to come largely from sources outside Rwanda. Funding has been provided primarily by Caritas chapters in industrialized countries.

Observations and lessons learned

There can be no "ideal" response to the loss of a parent, only better or worse alternatives. In general, placing a child in an existing family willing to provide care would be a better approach, and the social assistants do explore this possibility before children are placed in a family home. Attempts to create caring family units do appear to be working.

There are, however, two concerns that arise in connection with this model: money and continuity. There is no prospect for the family homes to become self-sustaining. Their continued existence depends on the ability of Caritas Rwanda or some other body to provide ongoing financial support. While Caritas Rwanda has had very strong support for the programme from several other Caritas chapters, there is no assurance that financial support can be maintained even until those children in the existing homes reach an age when they can support themselves. The programme is dependent on the capacity of Caritas Rwanda to raise sufficient funds every year, the same situation almost every NGO programme faces globally.

The possible departure of a mother is another vulnerability of a family home. The loss of a surrogate mother, after the loss of the natural parents, would certainly be traumatic for children. This risk is minimized, however, through careful selection of mothers. Staff turnover in a traditional orphanage would likely be much greater.

Although the family home programme is explained to the natural parents when the need for eventual placement of the children becomes clear, there was no attempt to have the family home mother meet the sick parent. If this would be acceptable to the natural parent, it would allow important information to be passed on to the family home mother and possibly ease the concern of the natural parent about the children's future.

It may be possible to implement the family home approach at a lower per capita cost. A Catholic sister in the town of Butare, where the cost of living was reported to be somewhat higher than Kigali, has initiated a family home with the support of a European NGO at the annual cost of US$207 per child. The lower cost per child would make it possible to serve a greater number of children with a given level of funding, but if too little is provided, it could increase the risk of the mother leaving.

Two other aspects of the approach taken by the sister in Butare are significant. As a trained nurse, she provides home-based care to persons who are ill. When she assists a father who is terminally ill and who is not married to the mother, she actively encourages him to have the marriage registered by the authorities. This benefited children after the father's death by giving them the legal right to inherit their father's property. In some cases, it also led to acceptance by the father's family and the possibility of placement if the mother died. The sister has also involved an attorney to protect the inheritance rights of orphaned children and to register them in the new community in which they are placed after the death of the parent.

DOMINICAN REPUBLIC

Background

Statistical profile	
Total population (1992)	7.5 million
Children under 16 years (1992)	2.9 million
Population growth rate (1980–1992)	2.3%
Population in absolute poverty (1980–1989)	
– rural	43%
– urban	45%
Population urbanized (1992)	62%
Average annual growth rate of urban population (1980–1992)	4.0%
GNP per capita (1991)	US$940
Average annual growth rate of GNP per capita (1980–1991)	- 0.2%
Infant mortality rate (1992)	42/1,000
Daily per capita calorie supply as percentage of requirements (1988–1990)	102%
Primary school enrolment (gross) (1986–1991)	Boys—95%; girls—96%
Secondary school enrolment (gross) (1986–1991)	Boys—44%; girls—57%

The State of the World's Children 1994, UNICEF

Socio-economic and cultural context

Located between Cuba and Puerto Rico in the Caribbean, the Dominican Republic occupies the eastern two thirds of the island of Hispaniola. Haiti occupies the western third. Poverty is a fact of life for most Dominicans. There is a large gap between rich and poor that has increased in recent years.

Tourism, manufacturing in free trade zones and sugar exports are key elements in the Dominican economy. Each offers opportunities for the spread of HIV and is, in turn, vulnerable to the effects of AIDS–related morbidity and mortality.

Though technically illegal, commercial sex work is extensive, practised freely and has wide social acceptance. It has evolved largely in response to the conjunction of poverty and tourism. There are estimated to be over 60,000 female sex workers in the country and a much smaller group of young male sex workers. A study recently commissioned by UNICEF estimated that there is an overlapping group of more than 25,000 child prostitutes in the country.[19] Some work in brothels, while others, who do not necessarily consider themselves commercial sex workers, frequently sell sex for money elsewhere.

The AIDS epidemic

AIDS was first recognized in the Dominican Republic in 1983. Initially identified primarily among gay and bisexual men, HIV has infected an estimated 3.5% of commercial sex workers and has begun to spread into the general population. Commercial sex work has been a driving force in the epidemic, and heterosexual contacts have become the primary means of HIV transmission. Almost 1% of the adult population is thought to be infected with HIV.

The tourist industry is the country's main source of foreign exchange income and a contributing factor in the HIV/AIDS epidemic. The Dominican Republic has been a popular destination for sex tourism from both the Americas and Europe.[20] A recent study comparing samples of HIV–positive and HIV–negative Dominicans found that having had sex with a tourist was the greatest overall risk factor for HIV infection among women, even more significant than having engaged in commercial sex work.[21]

Most AIDS cases have been identified in urban areas, but an increasing spread in rural areas appears likely. Factories in the free trade zones, which have begun to contribute to the Dominican economy in recent years, have reportedly attracted commercial sex workers from Santo Domingo, posing the risk of the rapid spread of HIV in these relatively confined populations. Significant HIV rates have been measured in the *batayes*, the rural camps where sugar cane cutters live. In one *bataye* 5% of the Dominican cutters tested positive for HIV in 1987.[20]

Discrimination towards people with AIDS is a serious problem in the Dominican Republic. One survey found that 74% of those asked thought people with AIDS should be isolated and half thought businesses should not employ them.[20]

A recent projection suggests that the proportion of the Dominican population infected with HIV could increase to five and a half times the current level by the year 2000. This would mean some 300,000 new infections over the next seven years.

Child welfare services and policies

Because the AIDS epidemic in the Dominican Republic is not as advanced as in many of the other countries included in the study, it is only recently that AIDS–affected children have begun to receive attention from child welfare groups. Child-focused activities related to the epidemic have primarily been limited to AIDS education. The *Hogar Infantil* (described below) is one exception.

In November 1993, both houses of the Dominican parliament passed a law with provisions to protect the rights of people who are HIV–positive. If signed by the President, the law would prohibit, for example, the use of HIV testing in hiring or as a condition for retaining employment. HIV–positive children and children of infected parents could not be excluded from educational centres, public or private. The legislation calls for age-appropriate sex education, including information on HIV/AIDS and other sexually transmitted diseases in all schools.

The Hogar Infantil

Children's needs

The children's bright smiling faces are a testament to the effectiveness of the *Hogar Infantil* ("young children's home"). When they first began to come to this child-care and development centre, many had serious health, nutrition and behaviour problems. Developmental delays were common.

"Gordito", now healthy and hefty, is one of the children who has experienced a dramatic transformation. He was suffering from third-degree malnutrition and was listless and unresponsive when his mother first brought him to the *Hogar Infantil*. His mother and those of the other preschool children who come daily to the centre are former commercial sex workers who have decided to find another means of supporting themselves.

Most of the mothers are from poor rural families. Recruited to come to Santo Domingo in their teens or early twenties, they were usually told that they would be able to earn a good living as domestic workers. They soon discovered that commercial sex work was the "opportunity" they were being offered. Repeated pregnancies followed. Children are valued, and abortions are illegal. As a result, most of the *Hogar*'s mothers have two or more children.

Commercial sex workers often go out at night, leaving their children alone in the small rooms or shacks where they live. While physical abuse of the children who come to the *Hogar* has not been found to be common, serious neglect was. Some children were tied when left alone. Some suffered rat bites. Most were very poorly fed and experienced little of the interaction and stimulation they needed to develop in a healthy way.

The Adoritrices' programme

The *Hogar* has made a dramatic difference in the lives of the children it serves and, in many cases, in their mothers' lives as well. It is one component of a larger programme run by the Adoritrices, an international Roman Catholic order of sisters whose mission is to work with marginalized women. Their work in the Dominican Republic started in 1986, the sisters having come there from several countries. Within two years, they began to focus primarily on the risks of HIV infection faced by commercial sex workers and began visiting the brothels to talk with women about HIV/AIDS. They made regular visits to about 20 houses with Ministry of Health personnel who do testing for HIV and other sexually transmitted diseases.

The principal objective of the Adoritrices' programme is to help sex workers to secure another type of employment. Their visits to brothels and word of mouth have helped spread the word that they offer job training, social assistance and assistance with finding work. Child care and school placement are primary needs for most of the women. Some also need help with food or housing. With donated funds, the sisters have purchased eight small houses for former sex workers who are HIV–positive.

The sisters have workshops for training in sewing and beauty work and have been able to help some women move into paid employment in these areas. They also conduct literacy classes. The training workshops operate Monday through Thursday, and religious instruction and discussion are offered on Fridays. The Adoritrices have helped about 130 women to achieve full economic self-sufficiency and about twice this number to become at least partly self-supporting. In November 1993, there were about 110 women in the training programme. Unlike the situation in some other countries, a woman who decides to leave a brothel in the Dominican Republic typically is not constrained to stay by the owner. The primary barrier to leaving is economic.

Those for whom the Adoritrices are able to help find other work typically earn less than they did as sex workers. The assistance the sisters are able to provide with housing, food and other basic needs, as well as through the *Hogar Infantil*, helps make their wages go further. The route out of commercial sex work is not always direct, however. For some, financial pressures lead to intermittent involvement, if not full-time return.

Starting the Hogar

In 1988, the Adoritrices began to work in cooperation with Centro de Orientación e Investigation Integral (COIN). COIN is a national NGO with a multidisciplinary approach to preventing the spread of sexually transmitted diseases, especially AIDS. They have trained sex workers to become health promoters and have been active in various other areas of STD and AIDS prevention.

Although women needed day care for their children in order to be free to take part in training or work, existing day-care centres were not willing to take the children of HIV–positive mothers. COIN and the Adoritrices decided to develop plans for a child-care centre for this group.

In 1990, they submitted a joint proposal for such a centre to the Christian Children's Fund (CCF), a US–based NGO. CCF indicated its interest but wanted to see the programme give greater emphasis to the developmental needs of the children and to how they would be cared for when HIV–positive mothers could no longer do so. CCF initially provided a consultant who helped COIN and the Adoritrices incorporate into their plans additional measures to promote children's healthy development, as well as investigating possible local sources of future funding for the programme. Satisfied with the revised proposal and the prospects for the programme to secure support for its continuation, CCF committed start-up funds.

Named "*Hogar Infantil Santa Maria Micaela*" for the founder of the order, the centre opened its doors in September 1990 for children from seven months through four years of age. In addition to being underweight and frequently suffering from a variety of gastrointestinal and respiratory ailments, the children had psychosocial problems as well. They tended to be either aggressive or timid. Older children would sometimes knock down the younger ones. They would not respond to directions given by their teachers. Particularly troubling, they did not smile or show affection. Their language ability was often far below what would be appropriate for their ages.

Services provided: starting with the roots of the tree

The *Hogar* is located in a small house in a lower-middle-class neighbourhood. Colourful pictures and decorations give it a cheerful atmosphere. Of the 38 children (20 boys and 18 girls) coming regularly to the centre in November 1993, 6 were from the original group enrolled. Most of the first group have gone on to other schools, often with the help of the Adoritrices. While the order has provided vital direct services to the children of the *Hogar*, they also help their siblings and the children of other women in their programme with access to school, basic needs and special things like Christmas presents. A total of 250 children, including those in the *Hogar*, were on the sisters' list for regular assistance.

A typical day at the *Hogar* starts at 7:30 a.m. when mothers start dropping off their children. The children have breakfast, then play time for the youngest and class for the older ones. A psychologist comes some days to organize stimulation exercises for the youngest children and structured play to promote social and physical development for the others, while training the staff in the process. Every other day, the older children go to the playground of a local school. After lunch and nap time, secondary-school girls come to teach the children games, songs and dances. Showers and baths follow, and mothers start returning around 4:00 p.m.

Staff of the *Hogar Infantil* have responded to the children's needs in an interdisciplinary way. The director of the centre is a trained social worker from Colombia. She has developed a team approach involving three teachers and a psychologist as well as a Ministry of Health nutritionist and two part-time doctors provided by the Dominican Institute on Social Security. Support staff who do the cleaning at the centre are former sex workers from the Adoritrices' programme, some of whom are HIV–positive.

In addition to working on the individual needs of the children, the staff also concern themselves with the mothers. Every Friday they hold training sessions with mothers on topics related to children's health and education.

The children have often played a direct role in the transformation of their mothers. As the children have become more responsive and affectionate, their mothers have responded in kind. Initially, at the end of a day, mothers would simply come in, take their children and leave. Now they react to their children's laughter, play with them and interact with the staff. When the children return to the *Hogar* after the weekend, staff can see they are better fed and cleaner than when they first started to come to the centre. The teachers encourage the children to say nice things to their mothers when they come to pick them up. The first time in four years the staff saw one mother smile was when her child looked up at her and said, "Mother, you are very beautiful."

After the first year of the *Hogar*'s operation, CCF carried out an evaluation. It found that the children had improved dramatically in terms of their nutritional status and social behaviour and that they had made steady, measurable progress in psychomotor, language and cognitive skills.

While priority is given to admitting the children of HIV–positive women, other former commercial sex workers also send their children to the *Hogar*. Of the women the Adoritrices have worked with since starting their work in the Dominican Republic, about 30 have died of AIDS, 2 of them mothers of children in the Hogar. The children of the women who have died have been absorbed readily into families. Usually an aunt or a grandmother, or in some cases a neighbour, has taken them in. For some of those orphaned, the Adoritrices have provided material support and assistance with schooling.

Costs and resources

The high-quality services the *Hogar* provides make it expensive to operate, and funding is an ongoing concern. The monthly expenses of the *Hogar* are almost US$2,900. Salaries are the largest budget item, followed by rent, food, medicines and cleaning supplies. Since the end of 1992, when the CCF grant ended, funding has been very limited. The Ministry of Health covers US$804 of the salaries each

month. Other funds have come largely from individual donations. A Colombian women's association has also donated some equipment to the centre and gives varying amounts monthly.

Observations and lessons learned

The HIV/AIDS epidemic is not as far advanced in the Dominican Republic as in the African countries included in the study, but with heterosexual transmission having become the predominant mode, the same problems are beginning to emerge among children. Even though discrimination against people with AIDS is a serious problem, children are highly valued in the country and so far orphans have been taken in readily by relatives or friends. While the number of children losing their mothers to AIDS is expected to increase substantially, orphans may not become a highly visible problem for some time because many will be taken in by families scattered throughout rural parts of the country.

The children cared for in the *Hogar Infantil* have shown serious developmental problems related to poverty and neglect to which the centre has responded very effectively. While the centre reaches only a small fraction of the children of commercial sex workers in the country, it has drawn attention to the fact that they are at high risk and has shown how their needs can be met. Reaching such children throughout the country, irrespective of whether their mothers decide to leave commercial sex work, requires priority attention from the Government, international organizations and NGOs.

The estimated 25,000 children involved in prostitution are even more vulnerable than those whose mothers are commercial sex workers. Their safety, health and psychosocial well-being are at extreme risk. The AIDS epidemic makes preventive and remedial action to end child prostitution an even more urgent priority.

THAILAND

Background

Statistical profile	
Total population (1992)	56.1 million
Children under 16 years (1992)	18.5 million
Population growth rate (1980–1992)	1.5%
Population in absolute poverty (1980–1989)	
– rural	25%
– urban	10%
Population urbanized (1992)	24%
Average annual growth rate of urban population (1980–1991)	4.2%
GNP per capita (1991)	US$1,570
Average annual growth rate of GNP per capita (1980–1991)	5.9%
Infant mortality rate (1992)	27/1,000
Daily per capita calorie supply as percentage of requirements (1988–1990)	103%
Primary school enrolment (gross) (1986–1991)	Boys—86%; girls—85%
Secondary school enrolment (gross) (1986–1991)	Boys—33%; girls—32%

The State of the World's Children 1994, UNICEF

Socio-economic and cultural context

Even though Thailand has one of the fastest-growing economies in the world, there are still gaps in resources and in education that also affect the spread of HIV. Certain groups may be at greater risk of acquiring HIV infection, such as hill tribe villagers, low-income urban slum dwellers, illiterate and poorly educated individuals (particularly women), male and female sex workers, and injecting drug users.

The poorest region is the relatively arid northeast, which is also the most populous. From here thousands of people migrate to Bangkok to find work as seasonal labourers on construction sites and the like. Since the 1970s, the capital city has swelled from 3 million to 7.9 million people, of whom about a third live in slums. Many of the country's social problems—prostitution, child labour and drug addiction—are poverty-related. A high proportion of Thai girls in brothels are from the north and have been sold by their families to help them survive or pay off debts.

One of Thailand's great success stories of recent decades is family planning. The average family now has 2.2 children rather than the 6.5 of the 1960s. As far as the AIDS epidemic is concerned, the small family norm may mitigate some of the devastating social consequences experienced in Africa. It means that fewer children are likely to be affected by the death of a parent and left as orphans.

The AIDS epidemic [22]

Since 1984, when the first AIDS case was reported in Thailand, up to 600,000 people are believed to have been infected with HIV by early 1994. The projections are that 2–4 million Thais will have been infected by the end of the decade unless there is a significant change in behaviour.

Heterosexual intercourse is the predominant mode of transmission. Prostitution is widespread and extramarital sex for men is widely accepted. Today, Thailand is seeing more and more married women infected as a result of their husbands' affairs. At present, more men than women are infected with HIV, but this situation is expected to reverse in the next couple of years. The epidemic is more advanced in the north where up to 10% of pregnant mothers attending the antenatal care clinics were found to be HIV–positive in 1993.

In July 1993, the Institute for Population and Social Research at Mahidol University published the results of a study on children affected by the epidemic.[23] It painted a sad picture. By 1993, a cumulative total of 11,500 children were thought to have been infected with HIV, and 4,022 children had died of AIDS. The estimated 1,750 children who died of AIDS in 1993 accounted for approximately 3% of all under-five deaths that year. Given present trends, AIDS will account for a third of the deaths of under-fives and a quarter of infant deaths by the year 2000.

Regarding AIDS orphans, the study predicts that:

- By the year 2000, there will be approximately 86,000 children aged 12 years and under whose mothers have died of AIDS.
- The number of children exposed to the risk of being orphaned will grow rapidly over the decade of the 1990s. In the year 2000, there will have been over 350,000 children born to mothers infected with HIV, compared to only 5,000 in 1990. Most of these children will be less than five years of age.

Child welfare services and policies

The welfare of children is the responsibility of the Ministry of Labour and Social Welfare. The Ministry has a limited budget and works in partnership with NGOs in some of its services, such as fostering, adoption and children's homes. Some of the Ministry's existing services are suited to helping children affected by AIDS—and could be made more so without much difficulty. There are, for example, various welfare grants available to needy families, who can also apply for interest-free loans to help with children's education.

Many people are unaware of their entitlements. In addition, social status is very important and even if they know their rights, the poor often find it hard to approach civil servants. Another problem is that funds for family support are at present far too limited to meet the need. However, this service is expected to get a bigger slice of the social welfare budget in coming years, as the emphasis shifts away from institutional care for children in need towards strengthening the families and communities to cope.

The Ministry's adoption and foster services and its children's homes are also relevant to AIDS orphans. At any one time, there are 4,500 children, excluding the disabled, in institutional care. A few children are placed with foster parents, who are entitled to a monthly allowance of US$20 per child. Adoptions are handled through a Child Adoption Board and a number of specially authorized NGOs.

Viengping Children's Home, Chiang Mai

Viengping, meaning "city of the young", is the babies' section of Chiang Mai Children's Home, one of 14 such institutions run by the Government in Thailand. It is housed in its own modern buildings in the spacious gardens of the home on the outskirts of Chiang Mai. Its dormitories are bright and cheerful, with giant ladybirds and flowers painted boldly on white walls, and jumbles of toys in and around the cots and small beds.

Viengping caters for children from birth to seven years who come from all 17 northern provinces of Thailand. They are children who have been orphaned, abandoned or abused, and the first aim of the home is to rehabilitate them in their families or find them adoptive parents. The few who do not find a place within a family graduate automatically to the home for older children, where they can stay until they are 18 years old.

Viengping received its first HIV–positive baby in 1989. At the time, no one knew how to handle the situation. But a directive from the Department of Public Welfare made it clear that it was a responsibility they could not put aside, and they sent staff for special training.

In Bangkok, Thailand, children play in a day-care centre run by the Duang Prateep Foundation. If the chain of HIV transmission is to be interrupted, it is essential that children be given the facts about HIV and AIDS before they become sexually active.

Today 11 of the 96 little ones in Viengping are HIV–positive. They range in age from four months to four years. They play with the other children but are accommodated in a dormitory of their own. They have their own carers—a babysitter and a "development therapist" on the day shift, and two babysitters at night.

There are ten other babysitters and four development therapists at the home, as well as a psychologist. Five volunteers come once a week to help care for the children. There are also two social workers whose responsibility is to look into the background of the children received at Viengping, to try to locate the families and to arrange adoptions.

Initially, staff were reluctant to work in the HIV baby unit, but resistance has broken down with experience. Staff are given the added incentive of extra pay—roughly a third more money than they would normally get. Children who develop AIDS are at present transferred to a private home for such babies run by a local physician.

It costs the Government about US$44 a month to care for a child in an institution, and up to US$8 more for a baby, not including staff salaries. Viengping relies on support from NGOs as well as the Government, and partners include international aid agencies such as World Vision, as well as local NGOs and individual well-wishers.

Traditionally, children's homes provided much of the education to children in their care. But standards in government primary schools have improved with the prosperity of the country, and this is no longer the policy. Classes at the Viengping Children's Home are being phased out and the children sent to government schools in the local community. This is considered better for the socialization of the children, and today the emphasis is simply on providing them with a home life and a sense of security.

In 1992, a new programme was introduced to try to meet the emotional needs of the children more adequately. Under the scheme, volunteers are chosen to befriend children on a one-to-one basis. The volunteers, who need to be able to give their time on a frequent and regular basis, are screened carefully. The qualities looked for are maturity, affection for children, and a social conscience. Those chosen are given training, which is essentially a familiarization course with the home, its working style and the psychological problems likely to be encountered in its children. This is not surrogate parenting, said Ms. Saowapak Supanit, director of children's services at the Department of Public Welfare. The relationship they encourage is that of siblings, and in many instances the scheme has proved enriching to both the volunteer and the child he or she has befriended.

The Foundation for Agriculture and Rural Management (FARM)

FARM was started in the early 1980s by a small group of Thais with a desire to do something for the poor. Today, it has a central administrative office in Bangkok (where it works in a limited way with a nearby slum community), and field offices in the north and the northeast—two of the poorest regions in the country. Recently, it has started working with fishing communities in the south.

While FARM was not set up originally to respond to the AIDS crisis, its client groups are among the most vulnerable to HIV in the country, and its operating style makes it ideally placed to respond to the growing needs of AIDS–affected families and children.

FARM has a very small staff. From the beginning, its role has been one of adviser and facilitator rather than implementer in the development process of local communities. Its mode of operation is to help communities identify the major problems in their lives, their priority needs and the resources available to meet them.

Much emphasis is put on helping communities to organize themselves for self-help—into women's groups, youth groups, farmers' groups, etc.—and on leadership training. Often getting things done means working with local government officials, such as agricultural extension workers or public welfare staff, which poor people find hard. FARM helps them to make contact and open regular channels of communication.

In 1992, FARM started a new AIDS programme to complement its mainstream development work. The three-year pilot programme has the ambitious aim of radically changing behaviour to prevent HIV from overwhelming the poor rural communities with which it works. So far, the organization has held training sessions with all manner of people from housewives groups and teachers to monks, school students and local government personnel.

AIDS is just one component of the training sessions, alongside discussion of the groups' more immediate concerns. "This is very important," said FARM's secretary-general and founding member. "Village leaders tell us they've had so many people talking to them about AIDS and then failing to follow up with any activities that they're not interested in meetings about AIDS anymore. So, we have to address what they are interested in and just introduce AIDS as one subject."

A second part of FARM's AIDS programme involves extending support to affected families (see box). Information leaflets at public places such as clinics invite people to contact the organization. FARM then explores, on a case-by-case basis, what kind of help it can offer. So far, this has included small loans and advice for starting income-generation schemes, referral for confidential counselling services at the Provincial Health Office, help with medical expenses, and donations of food and milk powder for babies of infected mothers. FARM has also brought people with HIV/AIDS together for mutual support.

The programme has not yet specifically addressed the needs of children who will be orphaned in the epidemic. But, besides its support for income generation, it has an innovative "village bank" scheme which could prove important in this respect.

Indebtedness is a widespread problem in poor communities. In times of hardship, families are forced to borrow from moneylenders who charge exorbitant interest rates—typically 6–10% per month—simply because the families have no other sources of funds.

At special seminars, FARM describes the principles of village banking. Villagers are advised to form "savings groups" of no less than 20 members, to decide on the contribution each must make to start the fund off, the criteria by which loans will be granted, the interest rate to be charged and how the scheme will be administered.

"To people who are used to being on the receiving end with little control over conditions, it can be quite a revolutionary concept having something to lend," said the founder.

Usually, a committee elected by the savings group members runs the bank and processes loan applications. Taking collective responsibility for a new and complex system is a good way of avoiding tensions and abuse. Only members can

borrow from the bank. Interest rates are commonly about 3%, payable monthly, and members get a regular dividend from the profits of the scheme.

When a bank is running successfully, FARM tops up its funds with an interest-free loan of US$770 for a fixed term agreed with the savings group. In lending FARM's money to its members, the village bank is allowed to charge 2% interest per month. The rate is set by FARM, which stipulates that half of the interest be paid into the bank to increase its capital fund, while the other half be put aside into a separate "social fund" earmarked for the benefit of AIDS–affected families.

The idea is that, in time, FARM will be able to refer the families that now appeal to it for help back to their own communities, in the knowledge that funds are available. "This way it'll be the community looking after its own needs, not a hand-out from outsiders," said the founder.

Christian Outreach

In 1991, the British charity Christian Outreach started a pilot project working with AIDS–affected families in a slum area of Bangkok. The main focus is women and children, and this is perhaps the only NGO to be concerned specifically with who will care for orphans.

The project, entitled "Living with AIDS", is primarily an exercise in strengthening families to cope with the challenge of the disease. It provides basic practical support to people with AIDS in their own homes and educates them and their families in care procedures. No direct financial aid is ever given to families, and the aim is for the project team to withdraw as soon as families are able to stand on their own feet.

Clients are initially introduced to the programme by hospitals or clinics, or by other NGOs. Once a client has made contact, the support team from Christian Outreach visits him or her at home to assess the situation and needs—the physical circumstance in which the person lives, how many people share the house, who is working, etc.—and a support programme is worked out. This may include accompanying patients to hospitals, assisting with transport costs and perhaps medical expenses, providing basic food and clothing where absolutely necessary, representing the client's interests to government departments such as public welfare, and introducing the client to an AIDS support group. Christian Outreach also tries to help those who are unemployed find work and has built up a network of employers sympathetic to people with AIDS.

Often, the support team's first task is to encourage the patient to share his or her diagnosis with the family, because the best option for orphaned children is to be cared for within the extended family network. But this can be painstaking work.

Fear and prejudice against people with AIDS are still so strong that those affected live in terror of disclosure—even to their own relatives. Often clients are extremely cautious about allowing Christian Outreach staff to visit them at home in case the presence of strangers arouses suspicion in their neighbours.

The project has a case-load of 30 extremely low income families—about the maximum its small staff can handle. It has been involved in planning for the care of children in a few of the families, and so far all have been provided for within the extended family. At present, the project only has the capacity to help with the

Somporn's story

Somporn is 23, small, slim and very pretty. But her vulnerable appearance hides immense courage. She comes from a village in northern Thailand. Three years ago she married and settled down with her new husband to farm among her many brothers and sisters. The family was big and close. But Somporn's world fell apart when she became pregnant.

After a routine visit to the antenatal clinic, she was told there were irregularities, and advised to go to the local hospital. In an interview that remains fixed in her mind, the doctor told her she was infected with HIV.

Somporn had heard of AIDS, but it had never seemed relevant to her life and she had not taken much notice. Now she became obsessed with it. Was her unborn baby infected? Would her neighbours find out? Already she feared that her visits to the hospital had aroused suspicion. She told no one, not even her family. But the gossip began. She tried to kill herself. When she finally confided in her family, they were shocked that she had not shared her burden with them earlier.

Somporn's husband was tested for HIV and found to be positive. He believes he picked up the virus during a brief spell in the army nine years ago. But when and where are irrelevant now; Somporn has no desire to blame, realizing that AIDS is a horror that can creep into anyone's life.

In early 1993, she gave birth to twins. One baby died, but the other, only a kilo at birth, is now a chubby little girl of eight months. She gets sick from time to time, and her mother is racked with anxiety.

Somporn's attitude to life changed when she came in contact with FARM, which has given her the support she needs to care for her child. FARM gave the couple a grant to start rearing poultry, and Somporn has found new purpose, too, as an AIDS educator at the organization's training sessions. Her message to women is strong: "It's up to you to protect yourselves and your future children from AIDS. Talk to your husbands about sex, and if there is any reason to fear infection, insist on condoms."

In her home village, gossip has quieted down, and Somporn no longer thinks of killing herself. But sometimes the fear of disabling sickness preys on her mind.

planning process. But if Christian Outreach sees child-care arrangements breaking down for want of support to the carers, it will explore the possibilities of networking with other relevant NGOs. UNICEF is sponsoring an evaluation of the project.

Observations and lessons learned

The Thai Government's response to the epidemic has won a reputation internationally for being open and dynamic. Its guidelines and action plans are enlightened, with emphasis on community care for people with HIV/AIDS and on strengthening families and communities to cope with affected children.

But fear of AIDS still grips Thailand and is proving a serious stumbling block to good intentions. More government money is going towards building institutions for infected people than towards community care. Patients diagnosed with AIDS are still being referred, more often than not, to tertiary-level hospitals rather than treated in clinics or community hospitals. And many are treated as infectious and admitted to separate units, although this practice is changing rapidly. Until relatively recently, staff in the maternity unit at Bangkok's major Chulalongkorn Hospital tried to avoid attending women who were HIV–positive.

The predictions from the Institute for Population and Social Research at Mahidol University of the numbers of children who stand to lose their mothers in the epidemic over the next 10 years are alarming. But they form only one piece of the complex jigsaw, insufficient in themselves to underpin an effective response. In addition to the size of the problem, planners and policy makers need answers to the following questions: Who normally steps in to care for children when a mother dies? To what extent will the traditional coping mechanisms be able to absorb the problem? What will be the biggest strains on the extended family in caring for motherless children, and what kind of support will they need to be able to cope effectively? Where the traditional system fails to provide for children, what will happen to those children? How will children in difficulties come to the attention of the public welfare authorities or child-care NGOs? How will their association with AIDS affect their situation? And what will be their needs over and above shelter and material provision? How can AIDS–affected families access the support they are entitled to?

For many reasons, the lessons Thailand can draw from Africa as far as the likely impact of AIDS is concerned are limited. To take just one example, Thailand's much smaller family norm means that the burden of motherless children will be spread more widely: one is not likely to find many situations in which elderly grandparents are caring for 10, 15 or 20 grandchildren; or in which large groups of children are living alone.

In the absence of any real understanding of what the country is up against, almost no one has devised a programme to cater for the needs of AIDS orphans. While many NGOs working with communities have begun to tackle AIDS simply because it is too serious an issue to ignore, they have tended to focus on prevention. Those that have started to offer support to AIDS–affected families have, with few exceptions, not yet focused on the children who will be left behind.

The Chiang Mai babies' and children's home had a relaxed and welcoming air, and observation of the children suggested they felt at home and had things to occupy them. The exception was the HIV–infected babies' unit, where the staff were overburdened and babies crying for attention had to wait for it. As with other orphan homes, links with the community need to be strengthened, including volunteer activities with the children.

Institutions have inherent limitations in meeting children's emotional and developmental needs, and they should not be the model of choice when new services are being planned in response to AIDS. However, children's homes are bound to form part of the answer to the problem of AIDS–affected children just because they already exist. There needs, therefore, to be more consideration given to the new challenge. For example, segregating HIV–infected children and paying their carers a special bonus may reinforce stigmatization and prejudice. It is unnecessary and may be bad for the emotional and psychological well-being of the children.

Rather than developing new institutions, Thailand's resources might be better used, and children's needs met more effectively, through developing foster care, adoption and family-type small-group care—interventions that are already working well in other developed and developing countries. In Thailand, there is a well-developed database on children's welfare, as well as research capacity on HIV/AIDS issues. Thus, more research could be undertaken on the social impact of AIDS on women and children, and small-scale successes could be documented.

UNITED KINGDOM

Background

Statistical profile	
Total population (1992)	57.7 million
Children under 16 years (1992)	11.8 million
Population growth rate (1980–1992)	0.2%
Population in absolute poverty (1980–1989)	Data not available
Population urbanized (1992)	89%
Average annual growth rate of urban population (1980–1992)	0.2%
GNP per capita (1991)	US$16,550
Average annual growth rate of GNP per capita (1980–1991)	2.6%
Infant mortality rate (1992)	7/1,000
Daily per capita calorie supply as percentage of requirements (1988–1990)	130%
Primary school enrolment (gross)* (1986–1991)	Boys—106%; girls—107%
Secondary school enrolment (gross) (1986–1991)	Boys—82%; girls—85%

The State of the World's Children 1994, UNICEF

AIDS in the UK presents a patchy picture. Over two thirds of all reported cases have come from London, but there have been serious mini-epidemics in cities such as Liverpool, Edinburgh and Dundee. Those most affected have been gay men, followed by injecting drug users. However, there are signs that transmission of the virus through heterosexual intercourse has been increasing steadily. Surveys of women attending antenatal clinics in 1992 give rates of HIV infection ranging from 0.05% to 0.54% in London and from 0% to 0.1% outside London.

As of 31 July 1993, a cumulative total of 483 children had been diagnosed as HIV–infected, of which 133 had developed AIDS. No one knows how many chil-

*Includes children repeating classes and/or out of age range

Children whose HIV-infected mothers cannot look after them anymore are a tragic feature of the AIDS pandemic everywhere.

dren have been orphaned by AIDS, or how many are likely to be in coming years, because data on the dependents of people with HIV/AIDS are not collected systematically. Nor have national projections been made. AIDS is no longer a faceless disease in Britain, since it has been widely covered in the media and many people with HIV/AIDS have been prepared to share their personal stories. However, there is still a good deal of ignorance and prejudice, and many people with AIDS are too fearful of the stigma even to reveal their diagnosis to their own families. Some of the loneliest people with AIDS are members of ethnic minorities who already face racism and fear rejection by their own group, or immigrants or refugees who fear their condition might affect their right to stay in the country.

Child welfare services and policies

Statutory responsibility for the care of "children in need" rests with the Ministry of Health and its network of social welfare departments at the local government level. Some local authorities have explicitly recognized their duty towards children affected by HIV/AIDS by including them in the category of children in need. In providing care, the social welfare departments work closely with voluntary agencies in the field whose services supplement or complement their own.

The Children's Act of 1989 lays down the framework within which care should be provided and is broadly recognized as a sensitive and enabling piece of legislation. It stipulates that:

- wherever possible children should be brought up and cared for within their own families;
- parents with children in need should be helped to bring up their children themselves;
- children should be kept informed about what happens to them and should participate when decisions are made about their future.

The Act also has guidelines for fostering and adoption of children affected by HIV/AIDS. Prospective adopters have a legal right to all available information about the health status and medical history of the child they are taking on and its natural family. The Act suggests that in certain circumstances such information should be given, in strict confidence, to foster parents also to enable them to give the best possible care to the child.

However, where the child's HIV status is not known, the Act says that there should be no routine testing for HIV prior to fostering or adoption, nor should tests be carried out solely at the request of the prospective parents. Rather, AIDS counselling, and information on HIV infection and its management, should be part of the preparation of foster and adoptive parents for their role as carers. At present, there is no uniform policy among local authorities on disclosure of a child's or parent's HIV status to respite or foster carers.

Positive Options

Barnardos is one of Britain's oldest and biggest children's charities, helping some 20,000 children, young people and families a year. In 1987, the organization started considering how it should be responding to the new challenge of AIDS. Its research revealed that family issues were being neglected by AIDS organizations, which tended to focus on the sick or infected individual. "Generally speaking we found a lack of awareness about child care among specialist AIDS workers, while child-care workers were often unaware of the issues surrounding AIDS," said Joan Fratter, a founding member of Positive Options, the programme established by Barnardos to fill the gap.

Besides this new specialist service, Barnardos instituted a programme of training every member of its staff—from cleaners to directors and numbering thousands countrywide—about HIV/AIDS. The organization looked, too, at the issue of sex and health education for the children in its care.

Money for setting up Positive Options came from the Department of Health, and the new programme began operating from a small office in north London in August 1991. Today, it is staffed by a project leader, four social workers who are specialists in child care, two secretaries and a volunteer coordinator responsible for around 20 volunteers.

Positive Options offers two services, the Planning Scheme and the Secondment Scheme.

The Planning Scheme

One of the most pressing anxieties of parents with HIV is what will become of their children. For children, too, the distress of watching a parent sicken and die is

often compounded by uncertainty about their own future. The Planning Scheme is designed to help such families work out alternative care arrangements for when the parents are incapacitated by sickness or have died. The sooner satisfactory plans have been made and people's anxieties addressed, the sooner affected families can get on with living to the full whatever time is left to them.

The service is free, and is available to anyone, anywhere in the country, without referral. In practice, however, most clients come to Positive Options through referrals from doctors, hospitals, or other AIDS organizations. The Planning Scheme's independence and confidentiality are very important, for many people are reluctant, for various reasons, to approach the statutory services when they have AIDS. Some fear that they will lose control of their lives and that their children will be taken away prematurely by the authorities; some worry that the information will be shared with others, such as their children's schoolteachers; and some, particularly immigrants or refugees, fear that their condition will affect their right to stay in Britain.

Once contact is made with Positive Options, a social worker visits the family to assess the situation: the health of the parents; how many children are involved; the ethnic and cultural background; what help, if any, the family is getting from other sources. Each new case is taken to Positive Options' fortnightly Referral Meeting, where decisions are taken on the role the organization should play and who among its staff is best suited to take on the case.

Positive Options' involvement with families is supposed to be time-limited up to about six months, and clients are advised of this and other basic conditions of the service, in writing, when they are first taken on. But it has only proved possible in a very few cases for the social workers to disengage themselves within such a short period of time. Mostly, it takes a great deal of time to work out a suitable package of care. "We find we're dealing with people at all different stages of their acknowledgement of their HIV status, their willingness to plan and their confidence about disclosure of their condition," said one social worker. Sometimes getting past the denial or numbness stage to a situation where the parent can think rationally and contemplate the future takes much patient discussion and counselling.

Another reason why it has proved more difficult to disengage than expected is that Positive Options' work involves people revealing a lot about themselves at a time when they are especially vulnerable, and this tends to foster attachment and a degree of dependency.

Helping clients come to terms with their condition and ultimate death, as well as helping them decide whom to tell, when, and what to tell them is the preparatory phase. Positive Options staff believe that confidentiality and disclosure are complex issues for which there can be no hard and fast rules. In deciding whether

to tell children of their parent's condition, the children's age, level of understanding and capacity to deal emotionally and confidentially must be considered. As far as others involved with the family are concerned, it must be assessed whether disclosure or secrecy is in the best interests of everyone. It may, for instance, help a child's teacher to know the situation if she or he is having to deal with disturbed behaviour or poor performance in class.

The next phase is planning for the care of the children, and Positive Options helps clients identify their needs and explore the options for meeting them. It is a guiding principle of the organization that high priority be given to involving the children in decisions about their future and respecting their wishes as far as possible.

Most clients need to plan who will take over when they are temporarily incapacitated by sickness or in emergencies, as well as making provision for the long-term future of their children. The organization does not have child-care services of its own; its role is advisory and facilitative, i.e., to make clients aware of what is on offer, both in the statutory and voluntary sectors, and how to avail themselves of the services.

The most satisfactory option is for children to be cared for by relatives or friends of the family. If a parent has someone in mind, they generally need help in understanding the legal and financial implications. If there are no relatives or friends able or willing to care for the children, the Positive Options worker will explore the possibilities of foster care or adoption with the client. Finding a satisfactory arrangement can be a painstaking process, for the traditional foster and adoption services are not geared to the needs of AIDS–affected families. Traditionally, there is little or no contact between the natural parents and foster or adoptive parents—indeed, the tradition in adoption cases is for there to be a clean break with the child's past. But with a slow terminal illness like AIDS it is possible—and often in the best interests of the children—for the natural parents and the prospective adopters to have contact. Ideally, they will develop a friendship that will lay a solid foundation for the future of the children, giving them continuity with their past when the parent dies, as well as someone to share memories and the pain of loss. This has happened on occasion, but it requires a good deal of tinkering with the social welfare machinery.

Under certain circumstances, family members or friends who take over the care of a child for a sick or dying parent are entitled to financial support from the state. But because of bureaucratic requirements this, too, can be difficult to arrange. Making the most of the experiences and insights it is gaining in the field, Positive Options is also a strong advocate for change. "A big part of our work is making child-care services aware of the needs of HIV–affected families," said Joan Fratter. Positive Options staff take an active part in training workshops and seminars for and with local authority social workers and others.

The Secondment Scheme

Under this scheme, Positive Options child-care workers are seconded for two years at a time to work with other AIDS organizations to look after the interests of children in their client families and to help parents plan for the future. At present (October 1993), there are three such secondments: one with Positively Women, an agency set up by and for women with HIV/AIDS; one with a drugs and AIDS project called Turning Point; and one working with immigrant and refugee families.

A number of such organizations have volunteers working with families, some of whom are involved closely with kids. Yet, in most cases it is an *ad hoc* arrangement in which the volunteer is not adequately screened for such responsibility and children are potentially vulnerable. This is the kind of situation in which the Positive Options' worker will draw attention to the needs of children and suggest changes in the system to protect them.

Much of the seconded worker's time is spent working directly with children. "Kids who are coping with a dying parent need someone to talk to," said one of the seconded workers. "Dealing with their emotional needs is often too much of a burden for an ordinary family, yet there are very few professionals offering this service."

She told the story of one 13-year-old girl reunited after two years with her mother, who came to Britain as a refugee. She found her mother very sick and did not know for a long time what was the trouble. Since discovering it was AIDS, she has become very difficult to handle, misbehaving at school and with the family who help look after her. "I have been trying to give her time, to listen and to help her understand and accept her emotions," the child-care worker said. A Ugandan who has seen what is happening in her own country, she does not believe the work she does with children in Britain is a luxury only rich countries can afford. "Addressing children's emotional needs is vital to their healthy development everywhere, and need not be expensive," she said.

Though they work from the premises of the agencies to which they have been seconded, the child-care officers remain part of the Positive Options team and are in regular contact. They attend the fortnightly referral meetings and have access to Barnardos resources. Importantly, this working arrangement ensures that they have the support of colleagues in the same field, rather than being isolated among professionals with different concerns.

The role of volunteers

Positive Options has on its books 23 volunteers who undertake a wide variety of tasks for client families, from cooking, shopping and house decorating to babysitting and taking children to school or on outings. Funds come from the local authority's "opportunities for volunteering" scheme.

Anyone who expresses interest in working for the scheme is given a "Volunteer's Pack" containing information on HIV/AIDS and on the work of Positive Options, as well as leaflets on first aid, on personal insurances and on how to claim expenses. Prospective volunteers are advised to attend one of the open meetings held monthly by Positive Options for volunteers, after which those interested are interviewed.

The volunteer coordinator is particularly interested in motivation. "Some volunteers are attracted to the work because they are themselves HIV–positive, or they have lost a partner or friend to AIDS. If this is the case, I try to find out whether they have come to terms with their loss, because voluntary work is not the place to work out one's own problems," she said.

The services a volunteer can offer, as well as the amount of time they can give to the work, is recorded on their personal file, and volunteers are given basic training in HIV/AIDS before they start. When a volunteer starts work for a client, she or he is introduced to the client by a social worker and ground rules for the relationship are discussed in order to prevent either party from developing unreasonable expectations.

At the meeting, clients are asked for any special instructions. Some people, for example, object to their children's being given sweets. Or they have special dietary, cultural or religious requirements that must be respected. During the introductory meeting, it is established how much children or other family members or friends know of the client's health problems. And the duties and time commitment of the volunteer are also clearly established.

Working with AIDS–affected families is stressful, and Positive Options puts much emphasis on supporting its volunteers. They also meet regularly in small support groups to discuss their work and share experiences and advice.

Helping children to face death

An important part of the work of Positive Options' child-care workers is to help parents prepare their children for bereavement. Ignorance and uncertainty about the past can exacerbate the sadness children feel at the loss of their parents, and even become a barrier to healing. The child-care workers therefore encourage parents to make some very personal record of their lives, and of their times with their children, to leave behind.

Barnardos has even designed a special "Memory Store" for this purpose (though it is a deeply personal matter, influenced by culture, and some parents prefer a less-structured approach to preserving the past). The Memory Store is a strong plastic attaché case, inside which are drawers to hold small mementos, space for video-cassette and tape recordings and a loose-leaf Memory Book in which to

record personal information about the family, with space for a family tree and photographs, if desired. "Children often want to know things about themselves, like what time they were born, the first words they spoke and when they took their first step. And they want to know about the history of their families," said Joan Fratter. "We try to make parents aware of these wider needs of their children. But it can be a painful process, and we must let parents work through these things at their own pace."

Giving testimony to the value of the exercise, one young mother with AIDS told Positive Options: "My daughter is my one joy in a sea of sadness. Someone will take over my child. But I'm writing a diary about her so she'll know how much I loved her."

Coverage and funds

In its first six months of operation, some 30 families approached the Planning Scheme to discuss the future of their children. By April 1993, enquiries had reached 690, the organization had taken on 75 cases, and some 20 more were awaiting allocation to child-care workers.

Positive Options' budget for 1993–1994 is approximately £250,000. Of this, around £90,000 comes from statutory sources—the Department of Health and various local authorities, which, among other things, pay the salaries of the child-care workers. However, future funding is very uncertain since, in 1994, the money available in local authorities for HIV/AIDS work will no longer be specially earmarked for this purpose. Voluntary agencies such as Positive Options which have benefited from such funds will in future have to compete with many different claims for money.

Observations and lessons learned

In a population of around 57 million, the number of HIV/AIDS cases is small compared with countries in Africa, Asia, Latin America and even some other developed countries. AIDS and its consequences do not threaten to overwhelm the health or welfare services. However, although numbers may be small, the effect at the family level can be devastating.

As data on the dependents of people with HIV/AIDS are not collected systematically, very little is known about children affected by the epidemic—either the magnitude of the problem or the nature of their needs. Consequently, few local authorities as yet have services that are properly responsive to children in this situation.

The Kyelitsha Project

The Kyelitsha Project was started in 1990 with core funding from Barnardos. Its aim was to offer the local authority "bridging" care facilities for children aged 4–12 years whose fostering arrangements had broken down—sometimes successively—and for whom more satisfactory long-term arrangements were being sought.

The project combines a small children's home with around six places and a number of foster homes prepared, with regular support from Kyelitsha's social workers, to offer care to children who may be very disturbed. The project did not originally anticipate dealing with children from families affected by HIV/AIDS. It has found itself gradually drawn into catering for the special needs of such families, however—in particular for "respite" care, i.e., someone who can take on the responsibility of children when the parents are sick or otherwise unable to cope.

Social welfare departments have found it especially hard to organize respite care for HIV/AIDS-affected families because of the unpredictable—and so far relatively limited—nature of the demand, and the expense of keeping carers on call indefinitely. The project is trying to persuade the local authority of the need for a more flexible funding arrangement for such services. "We really need a global sum from which we can pay respite carers a salary, rather than simply billing the local authority for days worked," said project leader Suzannah Bedford.

Ms. Bedford is strongly against creating exclusive services for HIV/AIDS-affected families, both because of the danger of drawing attention to, and further isolating, people with a stigmatizing disease, and because it may well deter needy people from using the service. Kyelitsha's HIV-adapted services are part of a range designed to be as responsive as possible to any kind of needy situation in which children find themselves.

The project demands no formal qualifications for the job of carer. "Basically we look for people who have an obvious capacity for parenting, something to give a child, and whom we can train," said Ms. Bedford. The training given covers such issues as how to welcome a child to a strange new home, understanding a child's sense of identity, play, managing difficult behaviour, caring for a sexually abused child, and HIV/AIDS.

When asked by the social welfare department to place a child, the department's social worker will meet with the prospective foster family and a Kyelitsha social worker. If the placement is approved, the department's social worker will continue to have responsibility for the child, while Kyelitsha's worker will support the carer.

At present, Kyelitsha, led by Ms. Bedford, has a deputy project leader, one full-time and one part-time social worker, and the services of a psychotherapist on a consultancy basis. The project is filling a gap in child-care services that few had even recognized, and already the responsibility on so few shoulders is heavy.

Most of the problems faced by Positive Options, as a specialist AIDS organization, are administrative. Funding arrangements for the various services have sometimes proved too rigid to enable a speedy and satisfactory response to the needs of AIDS–affected families. The respite-care service in particular has proved unable to respond to sudden and unpredictable need. Local authorities say they cannot afford to keep carers on call indefinitely, especially since they have not yet experienced great demand for such a service.

Most foster and adoption services have not yet taken on board the idea of planning a placement for a child or children before their natural parents become incapacitated or die, though such a change of procedure need not present much difficulty.

Another area in which Positive Options has experienced difficulties is in getting police clearance for carers and volunteers who will be working with children. Prospective candidates are required to give police details of their addresses for the previous 10 years. If a person has moved around, the clearance procedure can involve a number of different police forces and take years rather than months to complete.

It is generally recognized that the best option for an orphaned child is to be cared for within the extended family. In many cases, suitable relatives are living outside Britain, yet there is no automatic mechanism by which local authorities responsible for the welfare of the child can extend support to such relatives. Such arrangements have been made in individual cases through the mediation of Positive Options, and now, as part of its advocacy role, the organization has drawn up proposals for a child-care scheme across national boundaries where this is in the best interests of children.

Another problem is that many state-employed social workers and carers still have not received training in HIV/AIDS, thus limiting the possibility of sensitive handling of, and places available for, children from affected families. Though most social welfare departments have an AIDS unit, there is sometimes little contact between specialist AIDS staff and others, such as child-care officers, in the same department.

It is in showing how an existing infrastructure for child welfare can be made to respond to the new situation created by AIDS that Positive Options, and to an extent Kyelitsha, offer important lessons. Many child welfare services, for example, only come into the picture once a child is in crisis. With AIDS, there is the possibility of services' stepping in before a crisis occurs. Positive Options has identified the critical moments, the critical needs and the action necessary to deal with them.

CONCLUSIONS AND LESSONS LEARNED

By the turn of the century, close to 10 million children will have watched parents die of AIDS. Many will have lost the most important people in their lives, the very centre-pieces of their small worlds. Experience in a number of countries has shown that there is no model response to this extremely complex problem, but rather a range of responses that are appropriate in different circumstances. Based on experiences in various countries, the Lusaka Declaration in support of children and families affected by HIV/AIDS was formulated to raise awareness. See Annex 2.

Few countries have yet come to terms with the reality and considered how they are going to meet the needs of children affected by AIDS. Studies have been undertaken and numerous articles published; for a list of these, see the bibliography.

It is the purpose of this report to raise awareness of the need for timely planning and to share insights afforded and lessons learned by the few who have already taken up the challenge. This section is intended to highlight the lessons and observations from the field that have broad relevance.

Situational analysis

Assessment of the scale and nature of the problem of AIDS–affected children

Systematic assessment, which would provide information on the number of children concerned, where they are, the circumstances of their lives and the nature of their needs, has been shown to be a vital stimulus and first step to effective action. (It was a key recommendation at the UNICEF conference on AIDS and orphans, held in Florence in 1991.[24]) Nowhere have the needs of affected children become a national priority before this process has been carried out. Yet, until the problem does become a national concern, anyone attempting to respond to the needs of children is doing so in a policy vacuum, an open field with no guidelines and often insufficient safeguards against the establishment of inappropriate services.

In Uganda, it was an orphan enumeration study carried out in 1989 by Save the Children Fund (UK) in collaboration with the Government that put the problem on the world map. Only when there were facts and figures to back up anecdotal evidence and the predictions that epidemiologists had been making for some time did people respond to a tragedy that had long been developing in hidden corners of the world. The pattern is repeating itself elsewhere.

Such studies are as important in countries only mildly affected by the epidemic as they are in those hard hit. Everywhere, children are facing parental loss and a crisis of care. Yet, in the absence of figures, concerned organizations have difficulty convincing governments and securing the necessary financial and policy support for AIDS programmes.

Gathering data about children affected by the epidemic need not be a costly exercise. Often, it is possible to gather relevant information simply by adding a few specific questions in the context of other socio-economic research, including censuses. There are many opportunities, too, for programmes working with people with HIV/AIDS to find out about children likely to be affected.

Understanding the economic, social and cultural context

The state of the national and local economy, the availability of resources, the size and structure of families, cultural expectations and obligations, and traditional responses to adversity will all have an influence on what interventions are most appropriate, desirable and feasible. A major lesson from the field is that there are no short cuts. Time spent on baseline surveys and on simply getting to know the community in which a programme is to be started is never wasted. If interventions are to succeed, target communities should always be partners in the process, involved in identifying their needs and in planning and implementing the programmes to meet them. One implication of this is that while lessons can be learned from other people's experiences, programme models cannot simply be transferred from one situation to another, no matter how similar the circumstances appear to be.

Identifying epidemiological factors

Determining who is most vulnerable, why, where they live and in what circumstances is very important for planning programmes for prevention and care, particularly in the case of AIDS, which is a singularly dynamic and volatile disease. Epidemiology is a predictive tool, and it is vital to use the information it yields to capitalize on the time-lag between infection and disease for planning programmes. Epidemiological projections allow for planning before the problem of affected children becomes overwhelming.

Caring for children in the community

AIDS–affected children should not be singled out for assistance

While it is appropriate to assess collectively the needs of children affected by AIDS, as a general rule such children should not be singled out as beneficiaries of programmes. To use available resources most effectively, it is appropriate for programmes to focus their efforts on communities badly affected by the epidemic. But it is potentially stigmatizing and socially divisive to distinguish between children affected by AIDS and other needy children in the same community.

Strengthening the capacity of families and communities to provide for children's needs

Ultimately, it will be the affected families and communities that find ways to cope with AIDS and with the social and economic damage that the illness inflicts. Those who seek to help must remain focused on this fundamental reality. A relief approach of providing directly for children's needs is generally not sustainable where the number of affected children is large. Wherever possible, resources should be directed to enabling families and communities to establish and maintain a sufficient economic base to provide for children's needs.

Community-level care raises awareness about HIV prevention

There are direct links between community-level care for people with AIDS, and prevention of the spread of HIV. Care within the community encourages awareness in the general population of the immediacy of the epidemic. It also helps generate a sense of control and restores hope. There is a vital link between these attitudes and a community's receptiveness to prevention messages.

The inherent limitations of institutional care

Under certain conditions where family-based care is not possible, some form of group care may be a necessary part of the range of services for children without parents, but the risks and limitations must be recognized. They rarely answer the psychosocial needs of children adequately. To develop in a healthy way, the young child needs an ongoing, trusting relationship with a specific adult who is the primary caregiver. Such continuity of care is almost impossible to ensure in an institution. On reaching adulthood, those who have grown up in an institution often find difficulty reintegrating into the community. They lack the network of relationships and informal support needed to weather difficult times. The dependency nurtured by institutional life also works against their becoming self-reliant.

Institutions are usually unable to cope with an expanding problem, such as that presented by AIDS, without sacrificing quality of care through overcrowding. They are relatively expensive to establish and maintain; the same resources would go much further if applied to care within the community, for example.

The availability of institutional care tends to undermine a community's sense of responsibility for children whose parents have died. Furthermore, once an institution has been created, it is very hard to change course to a better approach because its staff and supporters have vested interests in maintaining it.

Street children's organizations

In urban settings, street children's organizations may have valuable lessons to share with organizations concerned with children affected by AIDS. And it is now urgent for all organizations working with street children to integrate AIDS prevention and care activities into their programmes and to provide appropriate training on this issue to their staff.

Economic support for families and communities

Efforts to support sustainable coping strategies among families will be very different in urban and rural settings. The fundamental issue most AIDS–affected rural families face is how to maintain agricultural production. The resource of land remains despite morbidity and mortality, and the question is how to make it productive. The essential resource of an urban family, however, is the capacity of its members to generate income, which is directly reduced by illness and death from HIV/AIDS. In cities, the question is how to help families generate cash.

Rural areas

In rural areas, helping to compensate for the adult labour lost to illness and death might involve the introduction of:

- new technologies, for example, animals or machines to till the land;
- less labour-intensive crops;
- methods, such as new seed varieties or cropping methods, to maintain or increase crop yields;
- revolving credit schemes to enable families with land but with insufficient adult labour to hire someone to do heavy agricultural work; or
- freeing available labour from other tasks by introducing new water points or fuel-efficient stoves.

There is a high degree of risk in introducing new agricultural approaches. This must be done with the active participation of experienced farmers in the area and tried on a limited experimental basis before being introduced on a large scale.

Urban areas

Helping urban families to improve their economic situation poses a different set of challenges even though the fundamental problem—compensating for lost adult labour—is the same. For some families, providing credit and technical support for small business enterprises can help them generate income, but initiating such a scheme requires substantial economic expertise.

In both rural and urban areas, in addition to helping families compensate for lost adult labour, community-level initiatives such as the following can be effective:

- developing cooperative day care to free adults for other work;
- developing apprenticeship schemes;
- organizing cooperative labour and marketing;
- supporting and monitoring the welfare of children on their own; and
- establishing group income-generating projects to provide funds to meet needs of children in the community.

Psychosocial considerations

Meeting the emotional needs of children affected by AIDS

Very little attention has been given to the emotional and developmental problems of children whose parents die of AIDS. Often, programmes are aware of their shortcomings but are not clear on how best to respond to such needs. There is a pressing need to involve professionals with relevant expertise to assess such needs and to help plan appropriate responses, drawing on what is known about how children recover from grief and loss. Key people in children's lives, including foster parents and schoolteachers, can be taught to recognize emotional distress and simple ways of helping children through encouraging them to talk or play and providing the nurture they require.

HIV–affected children may need to express their fears about what the future holds. They may feel that they are responsible for a parent's illness or death. They need to hear that they are not to blame and to see that there is someone who cares and will help them cope.

Enabling orphan siblings to stay together should be a fundamental principle of programmes assisting children. Breaking such bonds is an additional trauma. Siblings provide each other with mutual support, and these relationships are integrally linked with a child's sense of identity.

Problems begin long before the parent dies

In focusing attention on children orphaned by AIDS, it should be recognized that problems for such children begin long before a parent dies. Prolonged illness puts terrible strains on a family emotionally, psychologically and financially. Often, children know that a parent is dying long before the parent will acknowledge it. Yet, taboos against speaking about impending death and the stigma of AIDS inhibit them from sharing their sorrow and fear with anyone. Unvoiced, this pain is either not recognized or simply avoided by other adults in the child's life. Programmes to help affected children should look for ways of identifying those that are vulnerable as early as possible in the cycle of loss. Taking care of their needs and providing for their future while the parents are still alive not only mitigates some of the anguish for the children, it is also a great comfort to sick parents, who are often tormented with anxiety about what will become of their children.

Fear and stigma of AIDS

Fear of AIDS and the stigma attached to those affected remain enormous obstacles to the provision of services for children. Almost everywhere, these attitudes continue to frustrate imaginative and compassionate efforts to help people. In nearly all countries visited, people offering home-based care spoke of needy families fearful of being visited at home lest the presence of strangers rouse the suspicion of neighbours.

Because of fear and stigma, abandoned babies who test positive for HIV or are believed to be infected are being rejected or neglected by hospitals and mainstream children's homes—often despite enlightened national policies. In some cases, orphans are not being taken in by relatives in the traditional way, and sick parents are being denied the chance to plan for their children's future care because they are too afraid to tell anyone they have AIDS.

There is no quick solution to this problem. Governments must set examples and take a lead through openness and enlightened policies that discourage isolation of infected and affected people under any circumstances. The media can also do a great deal to reduce fears and myths about HIV/AIDS by providing facts, reporting on the human dimensions of the epidemic at the individual and family level and describing how families and communities are coping and supporting each other. Experience shows that, ultimately, seeing neighbours, friends and family members affected by AIDS is the most powerful factor in softening nega-

tive attitudes. Homes and hospitals that are caring for infected people, for example, should encourage contacts with families and the local communities so that people can learn by example that their fears are unfounded.

Though "going public" in an atmosphere of prejudice and hostility requires immense courage, it is hard to overstate the part that people with AIDS themselves can play, have played and are playing in changing attitudes.

Programme issues

Building on existing structures

The prime responsibility for social welfare rests with governments. It is their duty to develop the national policies and laws that form the framework within which all welfare activities take place. Wherever possible, efforts should be made to strengthen the administrative structure, both locally and nationally, so that it can function effectively. Inadequate resources and lack of administrative capacity frequently prevent them from carrying out their vital role effectively. Nevertheless, before thinking of establishing new and independent structures to address the problem of AIDS, governments and donors should consider rehabilitating or strengthening existing structures.

Flexibility

If programmes are to respond quickly and effectively to children's needs, they must have maximum flexibility. The course of AIDS—both for the individual and at the collective level—is uniquely unpredictable. This means there must be scope to switch funds from one activity to another that is more immediately relevant and scope to change plans as the situation on the ground changes or in the light of experience.

Donors, too, need to be flexible—in the criteria they set for funding, in their assessment of proposals and in the type of activities they are prepared to support. It is a common complaint amongst AIDS workers in the field that the too-rigid demands of the large international donors preclude many promising grass-roots programmes from obtaining funds.

Funding

Innovative and creative funding mechanisms should be devised to facilitate the support of very small-scale community-based projects which may be among the most effective and sustainable. If support cannot be provided directly to these very small initiatives, an umbrella organization to coordinate the activities of a

number of small projects and to administer funds from large donors may be very useful. UCOBAC's grants bank in Uganda is a successful example of how this can be achieved.

While the ability to be self-sustaining should be a consideration in all programmes and a prime long-term objective, many programmes that address the needs of society's most vulnerable groups will never be self-sustaining and will require ongoing external support.

Relief and development should not be seen as mutually exclusive approaches. In many instances, basic needs of food, shelter and medical care must be immediately satisfied, but as the magnitude of the problems increase, funds will be stretched extremely thin and priority will have to go to long-term strategies to enable families and communities to support their children themselves.

Grass-roots and umbrella organizations

Often, the groups best placed to strengthen family and community capacity are small grass-roots organizations. In an area heavily affected by AIDS, there is often a proliferation of small-scale responses (this may include even one person with a good idea). The collective impact of such efforts can be enormous. However, the multiplicity of actors involved in an effective response to the needs of AIDS–affected children requires a strong coordinating structure. An umbrella organization can facilitate links between concerned government ministries, United Nations organizations, international and national NGOs, and grass-roots groups. Its activities can include information exchange, needs assessment, skills sharing and training, resource sharing, policy development and coordination of activities. Such a coordinating structure can give a voice to community groups that would not otherwise be heard at higher levels.

Laws and policies

Existing laws and policies create either an enabling or a disabling environment in which to address the needs of AIDS–affected children. For example, laws that criminalize destitute children hamper efforts to provide appropriate services and information that may be vital to their survival. Inheritance laws can protect the assets of widows and parentless children or leave them vulnerable to loss of property and perhaps even their place in their communities. Laws protecting young girls from abuse in the context of HIV transmission have made their appearance in only a few countries, and even in those, enforcement is problematic.

Particularly significant are policies on HIV testing of children. This is an important issue that tends to be clouded by emotion and prejudice. In a number of

countries, testing certain categories of children—for example, abandoned children and those about to be placed in foster care or adopted—is a matter of routine. Testing should only be carried out if it is clearly in the best interests of the child. The fears of guardians and foster and adopting parents should be addressed through counselling. Training in the care of infected children is of paramount importance. "Psychosocial research should examine patterns and consequences of HIV disclosure within and outside the family and among various communities and cultures."[25]

AIDS is qualitatively different from other causes of parental loss, and existing services—even if they are capable of bearing the extra burden—will need adapting. Furthermore, policies need to be elaborated to protect the interests and human rights of AIDS–affected children, however few their number. To give just two examples, there need to be clear policies on the rights of infected children to attend schools, and to be placed in foster care or adopted.

The economic burden of families and children affected by AIDS might be alleviated by ensuring that their inheritance rights are protected. This would ensure that they have means of survival and economic livelihood, particularly in rural areas. In Tanzania, for example, local law and policy makers are taking initiatives independent of national land tenure law reform to protect the rights of orphans and widows.

Leadership and commitment

Often good programmes are the result of dynamic leadership and extraordinary commitment from those involved, either as staff or volunteers. These are qualities found time and time again; although they cannot be planned for, they should not be underestimated, nor should they be exploited. Recognition of people's input is important. So, too, is recognition of the unusual stress involved in working with AIDS–affected families. Burn-out is a very real threat to people whose daily lives are spent with the sick, the dying and the grieving, and watching the slow disintegration of families. All programmes should give thought to how best they can support their staff emotionally and psychologically, and should give them regular time off to restore their equilibrium.

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ANNEX 1

Projections of motherless AIDS orphans under 15 in six countries[1]

COUNTRY Years	LOW ESTIMATES		HIGH ESTIMATES	
	Number	Percentage	Number	Percentage
Uganda				
1995	220,000	1.5	460,000	3.3
2000	410,000	2.1	880,000	4.9
Zambia				
1995	180,000	2.9	310,000	4.6
2000	320,000	4.0	490,000	7.1
Kenya				
1995	210,000	1.1	310,000	1.7
2000	380,000	1.5	580,000	2.4
Rwanda[2]				
1995	70,000	1.2	150,000	2.3
2000	140,000	1.6	280,000	3.4
Dominican Republic				
1995	5,000	0.15	16,000	0.4
2000	12,000	0.27	40,000	0.9
Thailand				
1995	15,000	0.06	30,000	0.14
2000	30,000	0.11	100,000	0.44

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1. This table contains range estimates of the cumulative number of children whose mothers have died or will have died of HIV/AIDS before the child reaches the age of 15, and the estimated proportion of those children who remain in the population 0–14 years in the years 1995 and 2000.

2. The estimates for Rwanda do not take into account the population effects of the massacres that occurred in 1994.

ANNEX 2

Lusaka Declaration: support to children and families affected by HIV/AIDS

A workshop on support to children and families affected by HIV/AIDS took place in Lusaka, Zambia, from 1–4 February 1994.[1] Organized by the Centre International de l'Enfance with the French Ministry of Foreign Affairs, the workshop involved fieldworkers from eight African countries (Botswana, Kenya, Malawi, South Africa, Tanzania, Uganda, Zambia and Zimbabwe) working in 27 NGOs, and representatives of international organizations (WHO/GPA, UNICEF, UNDP, EEC). This was an occasion to share experiences and to make the following commitments:

Assessment of the problem

An assessment of the magnitude of the problem of children affected by HIV/AIDS is always necessary, but cannot be restricted to whether their parents are dead or not. Indeed, such a restriction would not reflect the complexity of the consequences for children affected by AIDS in that they start experiencing physical, social and psychological needs long before their parents' death. Furthermore, the child's HIV status should not be a factor in assessing the magnitude of the problem. The community should be involved in the assessment of the problem and implementation of a resultant project.

Living quarters for orphans

Whereas orphanages cannot be phased out, new orphanages should be discouraged. The existing few should be consolidated and strengthened to support emergency and difficult settlements. Global commitment is sought to reduce their growth in numbers and to support alternatives such as the extended family, family homes (support to women of the community so they can live with and care

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[1] For more information on the Lusaka Declaration, please contact Dr. Eric Chevallier at the International Children's Centre, Paris Tel. (33)1 45.20.79.92; Fax. 45.25.73.

for orphaned children in the family), and foster parenting and/or adoption (where priority is given to fostering or adopting children by families in their community).

Direct material and financial support

Families affected by HIV/AIDS are often in dire need of financial and material support. Past experience has shown that relief, though at times necessary, should be short-term and limited to critical circumstances in order to avoid family dependency. Instead, after determining feasibility, NGOs should endeavour to give support to activities that encourage self-reliance of people in need.

Support and home-based care

Home-based care is desirable, not only due to the lack of resources in hospitals and the high cost of hospital care, but also because it is an opportunity for patients to be received within the warmth of their family and community. The family and community should be supported and educated to systematically plan to complement and help each other in provision of care to prevent overburdening a few, especially women.

Basic skills transfer

In many instances due to AIDS, children are deprived of parental guidance before they develop their own survival skills. All efforts and support should be given to families in need in order to facilitate the transfer of skills from parents to children through counselling, education, sharing of experiences and social support.

Schooling

Experience has shown that children affected by HIV/AIDS are often deprived of and/or denied basic education. Basic education is the right of all children irrespective of their HIV status. Educational systems should promote the reorganization of curricula to include extracurricular activities which promote the acquisition of vocational skills. Rather than charging fees to needy children, schools should be subsidized to provide free schooling to the poorest children. School authorities should assist the children through provision of time and resources to meet their medical and social needs while assuring that their educational training needs are met. Non-formal education should be promoted, especially for school drop-outs (e.g., street children and teenage mothers).

Vocational training

Children of HIV–affected parents are often obliged to stop their formal education prematurely in order to provide care to their families or to earn their living.

There is therefore a great need to train older children in appropriate and marketable skills so as to enable them to earn a living. This can be accomplished through vocational training or apprenticeship, after assessing the child's preferences and abilities.

Income-generating activities

Due to the socio-economic impact of HIV/AIDS, and in order to avoid dependency, there is a great need for income-generating activities. Experiences have shown that families affected by HIV/AIDS often have great difficulties implementing successful income-generating activities by themselves. Communities should be involved in implementation and monitoring of income-generating activities together with affected families, and with the support of NGOs. Failures in income-generating activities are often due to a lack of feasibility studies (e.g., outlet analysis), training on project proposals and planning implementation. There is a need to explore innovative alternatives in this field. This applies also to helping commercial sex workers affected by HIV/AIDS to seek new ways of life.

Legal support and laws

Experience has shown that the legal and human rights of children in need and families affected by HIV/AIDS are very often broken. In many cases, the families are unaware of their rights, of existing laws or of means to implement them. Governments, communities and NGOs must provide information about those laws and support children in need and families in exercising their rights. Moreover, in some countries, existing laws do not support the vulnerable. Governments and legislators should urgently revise existing laws to adequately accommodate the needs of people affected by HIV/AIDS.

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